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ABSTRACT

Relationships between parents of children with special needs and their children are profoundly impacted by the child's special needs. Literature identifies several discrepancies in reported outcomes of these stressors and also speaks to the impact on overall marital satisfaction in these couples. In this project literature findings were reviewed, variables which influence the effects of having a child with special needs were identified, and an 8-week program for couples with a child with special needs was developed. The program explored various issues pertaining to having a child with special needs, identified how these impact on the relationship, and offered some coping strategies and insights to enhance the marital relationship, thus providing a service which has been lacking in traditional parent support initiatives. The participants in the group responded favorably to the process and with regard to their experiences in the group. Appendices account for approximately one-quarter of the document and include handouts, questionnaires, and other documentation used in the group. Contains 96 references. (JBJ)

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**IDENTIFY AND ALLEVIATE THE RELATIONSHIP STRESSORS
EXPERIENCED BY COUPLES WITH CHILDREN WITH SPECIAL NEEDS**

by

Richard Gregory

Cohort 7F

A Practicum Report Presented to the
Master's Program in Child Care, Youth Care, and Family Support
in Partial Fulfillment of the Requirements
for the Degree of Master of Science

NOVA UNIVERSITY

1995

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Authorship Statement

I hereby testify that this paper and the work it reports are entirely my own. Where it has been necessary to draw from the work of others, published or unpublished, I have acknowledged such work in accordance with accepted scholarly and editorial practice. I give testimony freely, out of respect for the scholarship of other workers in the field and in the hope that my own work, presented here, will earn similar respect.

July 7/95 Richard Gregory
Date Signature of Student

ABSTRACT

Identify and alleviate the relationship stressors experienced by couples with children with special needs. Gregory, Richard P., 1995: Practicum Report, Nova Southeastern University, Masters Program for Child Care, Youth Care, and Family Support. Descriptors: Parents/ Parents of Children with Special Needs/ Children with Special Needs/ Families with Special Needs/ Handicapped Children/ Couples/ Couples with Children with Special Needs/ Couple Counseling/ Couple Issues/ Family Stressors/ Family Issues.

Relationships between parents of children with special needs are profoundly impacted by the child's special needs. Programs have traditionally focused on what parents need to do to maximize their child's development. Such programs have failed, however, to give attention to the impact that having a child with special needs has on a family or the importance of nurturing the relationship between the parents.

The literature identifies several discrepancies in the reported outcomes of these stressors and also speaks to the impact on overall marital satisfaction in these couples. There are several variables which influence the impact of a variety of stressors, and several theoretical approaches which can be drawn on to address these issues. In this project the writer reviewed the literature findings, identified variables which influence the effects of having a child with special needs, and developed an eight week program for couples with a child with special needs. The program explored various issues pertaining to having a child with special needs, identified how these impact on the relationship, and offered some coping strategies and insights to enhance the marital relationship, thus, providing a service which has been lacking in traditional parent support initiatives.

The participants in the group responded very favorably to the process and with regard to their experiences in the group. This group will be incorporated - with recommended changes - into the family support component of the agency as a regularly scheduled program, being offered once in the fall and again in the spring of each school term.

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CHAPTER I - INTRODUCTION AND BACKGROUND

I THE WORK SETTING

The program is a private, not for profit, school providing educational services for children between the ages of 2 1/2 and 9 years in an inclusive environment. There are approximately 440 children in the junior kindergarten, ECS, and grades 1, 2, and 3 programs. Approximately half of the children have special needs, ranging from diagnosed diseases, syndromes, and disabilities to speech and other developmental delays. The program follows a transdisciplinary model and, in addition to classroom teachers and support staff, has a team of occupational therapists, physical therapist, speech and language pathologists, psychologists, and a family support worker.

II THE ROLE OF THE FAMILY SUPPORT WORKER

The family support worker works primarily with the families of children with special needs but is also available to the families of typically developing children. The duties of this position include coordinating a variety of programs for families, the provision of individual, family, and group counseling services, resourcing, advocating, and support work.

CHAPTER II - THE PROBLEM

I PROBLEM STATEMENT

Many Canadians - one in seven - have disabilities. The vast majority of them live with their families. Studies indicate that approximately 5% of all children are disabled in some way and the proportion with disabilities increases with age. Disability can involve impairment of cognition, sensation, movement, stamina, disfigurement, and conditions associated with social stigma. For more than one third of these children, their disabilities are severe enough to limit their participation in school, play, and other normal activities. Parents who are raising and caring for children with disabilities experience increased stress and a greater financial burden (The Vanier Institute of the Family, 1994).

Families are no strangers to stress. Families of children with special needs have the same stresses as families of typical children, but accentuated because of the special needs of their children. Traditional programs tend to offer parents information on child development and on how to work with their child; provide parenting programs to suggest ways of coping with the special need; and give information pertaining to the parents' relationship with their child. There are few programs which explore the impact that having a child with special needs has on the relationship of the parents or offer ways for the parents to enhance their marital relationship.

II DOCUMENTATION OF THE PROBLEM

For the past four years as the family support worker at Renfrew Educational Services, I have had the opportunity to work with families who are experiencing marital breakdown. Often times the issues identified as creating difficulties are those which can be attributed to having a child with special needs. I believe that the demands of having a child with special needs are one among many factors which may exasperate marital conflict. There are conflicting findings about whether the incidence of divorce is higher in families with chronically ill children (Lansky et al., 1978, Masters et al., 1983,

Murphy, 1982). In contrast to normal family developmental patterns, families with a disabled child were found to experience higher levels of marital disintegration (Farber, 1960). Some researchers found that divorce rates are twice as high among couples who have a handicapped child (Tew, Payne & Lawrence, 1974). Love, (1973) reports that the divorce rate among parents of mentally retarded children may be triple the national average and suicide among this group may be double the national average.

Many other studies, however, conclude that marital separation and divorce rates are not higher for families of disabled children. Martin (1975) found that there was no significant difference in divorce rates and Sabbeth and Levnthal (1984) in a review of 34 studies of marital adjustment when a child had chronic illness, concluded that divorce rates were not higher than average although there was more reported marital distress. They suggest that some conflict and squabbles may be adaptive as a way of managing tension and difficult emotions and issues.

Marital satisfaction in couples with children with special needs is an issue that has received the attention of several family researchers. Results, however, have been inconsistent and contradictory. Friedrich (1979) indicates that the presence of a handicapped child was a significant predictor of marital stress; Waisbren (1980) found a strong relationship between the existence of a handicapped child and parental stress, but no predictive value; Friedrich & Friedrich (1981) show elevated levels of marital dissatisfaction; Holroyd (1974) found chronic and dysfunctional stress, particularly among mothers, while Cummings (1976) found such stress among fathers; and Davis & MacKay (1973) identified restricted social mobility and social relationships in parents of children with handicaps. Kazak and Marvin (1984) did not find a difference between parents of nonhandicapped seven to eight year olds and parents of handicapped seven to eight year olds in their perceived marital stress. Kneedler, Hallahanm, and Kauffman (1984) state that families of children with special needs do experience great stress, but they also learn to cope sometimes better than other families. These same authors believe

that many families become closer and stronger than they might have been otherwise. In a study of marital happiness of families of children with a variety of handicaps (Krause-Eaheart, 1981), approximately one-half of the mothers reported that the handicapped child did not affect their marriages. The remaining half of the mothers were divided into two approximately equal groups, one of which felt that the children had adversely affected their marriages and the other that felt that having a developmentally disabled child had actually strengthened theirs.

Parenting stress is not necessarily elevated in families of young children with disabilities compared to families of young children without disabilities (Frey et al., 1989; Gowen et al., 1989). Kazak and Marvin (1984) found that parents of children with handicaps reported more arguments over discipline but high marital satisfaction, indicating that higher stress does not necessitate dysfunction within the family.

III ANALYSIS OF THE PROBLEM

Heward and Orlansky (1984) indicate that the birth of a handicapped child or the discovery that a child has a disability is unquestionably an intense and traumatic event. Parents can differ widely in their reactions. Berdine and Blackhurst (1985) list such factors as religion, socioeconomic status, severity of handicap, parental knowledge, or order of birth that can all affect the parental responses of frustration, fear, disappointment, and uncertainty. The reactions and subsequent behavior of parents toward their handicapped child are complex issues. A child's handicap attacks the fabric of a marriage. It excites powerful emotions in both parents and acts as a symbol of shared failure, reshaping the organization of the family, thereby creating a fertile ground for conflict (Featherstone, 1980). Individual unhappiness can drive two people apart, even when they share many of the same sorrows. Practical reality reinforces the tendency to confuse the health of the child and the health of the marriage. The disability touches most of what parents do together, influencing the circumstances of sleep, work,

mealtimes, outings, vacations, and other components of family life. Chronic medical conditions take their toll on families, draining valuable family emotional, practical, and financial resources. The potential impact of the medical illness on the family's overall psychosocial and vocational functioning should command attention (Seinglass & Horan, 1987). If a child's special need constricts a couple's life at every point, the marriage becomes a prison (Featherstone, 1980). Even under the most favorable conditions, a disability usually changes the family organization and the systematic way a family functions as a group.

One of the most difficult lessons that parents of a handicapped child must learn is not to ignore their own needs when they make adjustments for their handicapped child. In his work with fathers of children with special needs, Don Meyers has found that only by keeping sight of their own needs and the needs of their other children will fathers be able to effectively meet the challenges and added responsibilities of raising a handicapped child. Families are dynamic systems, and in order to identify an effective coping strategy a parent must balance each family member's needs and resources, first listening for the family's pulse, then deciding upon a course of action to reduce stress (Meyers et al. 1985).

Some parents sink into a state of pathological grief, from which they do not seem able to recover. They become profoundly depressed and are unable to take any pleasure in life again. Home life and marriage may suffer, and other siblings inevitably feel the effects. This is not merely a state of continued sadness, which is normal, but a problem that needs expert help. It cannot be diagnosed purely on the basis of how long the parents have continued to feel sad or to have episodes of weeping and despair (Johnson, Uttley, & Wyke, 1989).

Robinson and Robinson (1976) state that patience, understanding, ingenuity, good humor, and strength are demanded in large measure from the parents of any youngster. Parents of a handicapped infant must make the same adjustments that all new parents must make to their new or expanded role as a parent. In addition, the mother and father

of an infant with special needs must also adjust to the infant's special needs. The situation may be more complicated and more hazardous, with the rewards of parenting more likely to be lost sight of. The parents must modify the expectations for the infant they had dreamed about and planned for. They must absorb new, and often confusing, medical information about the infant's condition, needs, and prognosis. The child's limitations, the special arrangements needed for physical care, training, and companionship, the disappointments and the lost dreams, all combine to create pressures which tend to disrupt the family equilibrium. The mother and father must work through waves of feelings of shock, denial, anger, grief, numbness, and depression (Meyers et al. 1985). Added to these pressures may be financial problems, tensions created by the child's immature self-control, handicaps in communication, and parent's own lingering doubts about their parenting practices. Thus, the relationship between a child and his or her family is potentially more complex and ambivalent than the ordinary one, as well as being more intense and prolonged.

Over the course of the infant's development, parents continue to experience cycles of elation and joy, as well as periods of fatigue, and feelings of doubt about their competence as a parents, of regret over the loss of their freedom, and general ambivalence. Even the most loving and well-adjusted parents sometimes have these mixed or negative feelings (Meyers et al. 1985). They will be affected by the child's behavior, their marital relationship, their relationship with their other children, economic difficulties, and job demands. They must face increased demands as parents, educators, advocate, and oftentimes nurses for their handicapped child. These are times when all parents regret the freedom they have lost, or experience hurt or sadness as part of being a parent. Even problems which exist in one form or another in many marriages strike exceptional parents with peculiar force and intensity because exceptional parents need support more than other people and because few couples expect a child's troubles to divide them (Featherstone, 1980).

The interminable chronic stress of caring for a head-injured child may well destroy the parents' marriage, their physical health and their careers. Furthermore, they live with the constant worry of not knowing who will take up this burden of care when they fall ill or die (Johnson, D.A., Uttley, D., & Wyke, M., 1989). These are issues that might be addressed as part of a long-term counseling and therapy program.

The bond of shared sorrow and trouble and of happiness wrung from ultimate pain can enhance a relationship. Raising a handicapped child - raising any child - entails a great deal of learning, and learning helps keep a marriage vital. The problem is to survive present pain and to find ways of alleviating the major stresses confronting a family. The difficulty is not that few parents cope, but rather, that few talk freely about the strains of their marriage, or the ways in which they have learned to meet them. Most marital problems are complex, even when approached with energy, insight, and humility, fixed patterns resist change (Featherstone, 1980).

A child's disability may reveal fault lines in a marriage that no amount of effort and understanding can rectify. Some marriages collapse - and this is not necessarily a bad thing. If a husband and wife's values differ fundamentally; if every act from folding laundry to choosing a therapy program requires an agonizing compromise; if anger washes over even the most sincere efforts at mutual support; it may be time to end things (Featherstone, 1980). Even a painful divorce can look good compared to a life of filled with continual, unresolved conflict.

Crnic, Freidrich and Greenburgh (1983) report that the degree of stress perceived by family members is mediated by coping skills that are mediated in turn by ecological systems. Ecological systems composed of an individual, that individual's family, peer group, and social institutions have a powerful effect on his or her ability to cope during any stressful situation. Coping skills that determine the level of stress experienced by the individual are influenced by feelings of helplessness or of being in control; perceptions of support available from social networks, both formal and informal, parental

health, energy and morale; parental problem solving skills; and practical resources such as financial income (Blacher, 1984; Featherstone, 1980). The model helps to explain why many researchers have concluded that even though the presence of a handicapped child generates some common reactions and feelings in a family, differences exist in the range and timing of those reactions and feelings.

Empirical research models and methods of analysis have largely tended to reinforce a fragmented view and have failed to capture the reciprocity of individual and family influences in the development, course and treatment of chronic illness. While a few adherents of family systems theory have rejected empirical investigation on the basis that it is not systemic, Walsh and Anderson (1987) argue that the problem, in part, is not existing methodology but our lack of skill and specificity in applying it. What is needed is more refined conceptualization of hypotheses and variables, and more sophisticated designs. Current methodological guidelines do not preclude the recognition of the influence of the investigatory and the research context, or a shift from simplistic linear associations of 'independent' and 'dependent' variables to complex multivariate analyses that more closely approximate life experience (Walsh & Anderson, 1987).

Research focusing on the need of families for remedial services presupposed the existence of a norm of the 'healthy' family life toward which people strive - the companionship family model (Gallagher & Vietze, 1986). Consequently, the research tended to focus on variables that pertained to the departure from this norm of family life. These variables include the degree of family disintegration, role tension and conflict, personality disorders, psychosomatic illness, inhibition of school and occupational success of parents and siblings, and so forth. In families of children identified as being mentally handicapped a common finding was that although parental suspicion of development problems evoked some anxiety, the critical point in parental turmoil occurred when the child was actually labeled as retarded (Gallagher & Vietze, 1986).

Rolland (1980) believes that a developmental framework and family paradigms are the most accurate way to view family dynamics and long-term illness. He looks at the family illness belief system, the family transgenerational history of coping with illness, loss and crisis, and the interface of the illness with the individual and family life cycles. Each individual develops and adopts a value orientation, a belief system or philosophy which shapes patterns of behavior toward common challenges of life. Beliefs provide coherence to family life, facilitating continuity between past, present, and future and a way to approach new and ambiguous situations such as a serious illness. A family's belief about what is normal and what is abnormal in relation to the average family will have far reaching implications in the context of protracted adversity such as a chronic disorder. Depending on which system we are speaking of, this phenomenon can be labeled as values, culture, religion, belief system, world view or family paradigm.

Commonalities across diagnoses in such areas as problem-solving, stress management, and coping tend to be overlooked because they are statistically insignificant in differentiating diagnostic groups, and are therefore deemed unimportant in understanding a particular disorder. Such data analysis and research design practices reflect the bias that continues to permeate the clinical field; interest in family is chiefly in its presumed causal role in the development or maintenance of major disorders. In considering such data "non-findings" important information is lost that may have considerable clinical value (Walsh & Anderson, 1987).

Reviews of research conducted prior to the early 1980's on family adaptation to the challenges of rearing a child with disabilities have noted a primary focus on mothers rather than on families and a general reliance on a simplistic deficit or pathological model of adaptation (Byren & Cunningham, 1985; Crnic, Friedrich, & Greenberg, 1983; Krauss, 1986). Such research assumed that rearing a child with a disability was inherently stressful and that affected families were a homogeneous group. Whereas most of the research over the past three decades has focused on a mother's point of view, there is

widespread consensus that the effects of rearing a child with disabilities or delays are not limited to mothers (Crnic et al., 1983). Family systems theories have emphasized that novel demands on any member of a family have reverberating effects on other members and on the family as an organizational unit (Walsh, 1980).

Literature on family stress theory assumes that stress (manifested as depression, social isolation, role restrictions, marital discord, etc.) is a signal of disequilibrium in personal or family functioning that may result from difficulty coping with either normative or nonnormative events (Pearlin & Schooler, 1978). As a marker variable, stress has been found to differentiate families of children with different types of disability (Holroyd & McArthur, 1976), levels of severity of disability (Beckman, 1983), available social support (Dean & Lin, 1977), and strategies for coping with provoking situation (Friedrich, Wilturner, & Cohen, 1985).

IV. VARIABLES OF THE PROBLEM

GENDER ISSUES

Similarities and differences in the adaptive patterns of both mothers and fathers of young children with special needs remain relatively unexplored. General stresses of parenthood are such that mothers and fathers of handicapped children share concerns experienced by all parents (Meyers et al. 1985). Shonkoff et al. (1992) in cross-sectional and longitudinal analyses yielded a consistent distinction between married mothers and fathers related to their patterns of parenting stress. Fathers reported greater stress associated with their feelings of attachment to their child whereas mothers reported more stress associated with the personal and familial aspects of parenting.

McGoldrick, Anderson and Walsh (1989) identify that recent researchers have found a continuing difference in the values of men and women about their marriages. Although during the courtship men are willing to spend intimate time with women, after marriage they tend to spend less and less time talking to their wives - often considering

doing chores around the house to be an adequate demonstration of caring and intimacy and feeling mystified about what women want when they seek more contact in marital relationship. Generally women do want intimacy and are frustrated by the limited degree of relating to their husbands' offer, causing husbands to evaluate the relationship as problematic.

In addition to these conflicting perspectives there are significant value differences equated to gender. Men value their wives looks more, while women consider their husbands' earning potential a major attraction in marriage. Men say that what is important in a marriage is their wives' sexual responsiveness and shared interests, while their wives say that the husbands' ability to get along with her family and friends is more important. Men generally rate their marital communication, relationship with parents, and sexual relationships as good, while women rate all of these as problematic. Married women experience more depression and more marital dissatisfaction than married men. In addition, women in traditional marital relationships have poorer physical health, lower self-esteem, less autonomy, and poorer marital adjustment than women in more equal relationships. Traditional marriages and family patterns are no longer working for women, and the statistics reveal their dissatisfaction. Basic to change is the notion that nurturing would not be the domain only of women and that work and money would not be primarily a male controlled sphere (Featherstone, 1980). Children's problems, however, preoccupy many women even after they rejoin the labor force while fathers seem better able to set domestic concerns aside and to focus on other pursuits.

Gender differences have been found to correlate with stress, with cognitive coping factors reported to have more influence on the adjustment of fathers than mothers of young children with disabilities (Frey, Fewell & Vadasy, 1989). Gumz and Gubrium (1972), Hersch (1970), and Love (1973) concluded that the impact on a father of having a handicapped child is different from that on mothers. Fathers appeared to accept the diagnosis with less emotion, to be more objective, less emotionally involved, and more

future oriented, worrying particularly about the long term economic support of the handicapped child. A prolonged period of denying the reality of the handicap appears to be common among minimally involved fathers who do not interact with the children often enough to be forced to recognize the severity of the problem.

Fathers of handicapped infants, as well as fathers of nonhandicapped children, are most effective in meeting their newborn infants needs by being aware of how the infant fits into the existing family system (Meyers et al, 1985). Other needs can be more difficult to keep sight of when the father is overwhelmed by the needs of the handicapped infant. In some families, the father's emotional difficulties are masked by the father's need to be stoic and control his emotions. Fathers have also been found to perceive their handicapped child as a threat to their self concept. Fathers who view their handicapped child as an extension of their own egos are apt to become isolated and to reduce or withdraw from social interactions (Illingworth, 1967). Men often find it difficult to express sadness or grief, and there are fewer socially acceptable ways for men to express these "weak" emotions (Meyers et al. 1985). If the infant's mother is experiencing shock or depression, the father may deny his own feelings in order to support his wife. Not only is it important that the father adjust so that he can develop a meaningful attachment to the infant, but the father must often times also help other family members cope with their feelings (San Martino & Newman, 1974). In many families the parents provide the model that siblings and other relatives follow in adapting to the infant's handicap.

Kazak and Marvin (1984) did find a difference between mothers of handicapped and nonhandicapped children in perceived satisfaction with parenting. Their results showed slightly higher degrees of marital satisfaction among the mothers of children with handicaps, but less satisfaction with parenting. Those mothers reported more feelings of depression and incompetence related to the added caregiving demands.

Cummings (1976) found in his study of 240 fathers of mentally retarded, chronically ill, and healthy children that fathers reported more stress than a sample of

fathers of similar children. He found that fathers of mentally retarded children may undergo long-term personality changes of neurotic type and have few constructive outlets for such stress. Fathers reported awareness of the negative aspects of the child's care but were involved in few of the rehabilitative aspects. Only half of the mothers and fathers in the study were couples, however, so such comparisons can only be suggestive, and no data are presented on the effects of either parent on the children.

These results contrast with those of Tavormin, Boll, Dunn, Luscomb, and Taylor (1981) who found that 133 mothers of diabetic, asthmatic, cystic fibrosis, and hearing impaired children reported both more problems and more involvement than fathers with their chronically ill children. The stress was clearly taking a toll on both parents, whose functioning fell between the reported for either normal or poorly adjusted parents on measures of personality styles, attitudes perspectives, and coping strategies. The type of child illness affected parental scores, reflecting a differential impact according to type of handicap. The indirect effects of one parent on another were not studied, nor were parental variables related to child outcome. In both studies, the effect of child characteristics is controlled by use of comparison groups of parents of children with differing handicapping conditions.

ROLES

The presence of a child with special needs can make the traditional division of roles difficult (Featherstone, 1974). The role differences can be the stage for certain sorts of conflict. Men who concentrate their energies on a career and do not discuss domestic difficulties with friends or colleagues, receive little preparation for exploring painful feelings at home. More limited exposure to children - both to their own and other people's - may permit them to ignore developmental differences that disturb their wives. Mothers usually feel the burden of care most acutely because many, following the traditional role for women, assume the major part of the care. A woman who sleeps and

eats at the pleasure of a handicapped baby may not be able to fit the disability into a larger perspective or to forgive her husband for worrying less than she does (Featherstone, 1980).

Most families distribute the necessary chores among family members, with the mother covering more bases than anyone else. Some families work out different patterns and experimenting with roles is a phenomenon of the time in both typical families and those with children with special needs (Featherstone, 1980). Whatever the arrangements, a disability can complicate parents' feelings about the domestic division of labor. A division of emotional labor can make husband and wife feel further apart than they really are. The division of domestic labor can magnify difference in somewhat the same way, by offering a mother and a father quite divergent means for coping with shared tragedy.

The balance of gains and losses in choosing to work at home, raising children, and maintaining a household, rather than working outside, obviously depends on many things. One of these is the quality of family life - the particular pleasures and pains involved in being with children most of the day. If a child taxes a mother's physical and psychological resources too heavily, she feels that she is giving more and getting less than she needs. Even if she sees her husband assuming certain responsibilities, she may resent his freedom and the regular breaks from "exceptional parenthood" that his job provides.

The traditional family in which a man works full-time while his wife assumes primary responsibility for their children, offers a man the opportunity to spend many of his waking hours in a world untouched by private tragedy, however good or bad that world may be in other respects. The diagnosis of a child's disability may reshape his vision of the world, but it rarely changes the way the world sees him; his on-the-job responsibilities continue as before (Featherstone, 1980). A job allows both an escape from their child's problems and a setting that helps to establish continuity in life. Outside

work helps people to avoid defining themselves exclusively in terms of a child's disability.

Women who stay at home full-time often find that a hurt child fills their lives and dominates their thoughts. Immersion in a child's immediate needs provides important opportunities for coming to terms with loss. The mother learns routines for caring for her child, finds help, locates services. Daily exposure forces her to confront her own doubts and to re-examine painful feelings (Featherstone, 1980). Frequent consultations with doctors and other professionals teach her whatever is known about the child's problems. Under favorable conditions these routines of caring build confidence and help a mother to work through her feelings. Levine and Ebert (1983) found that mothers assume most of the stress of the children's illnesses and thus protect fathers and, theoretically at least, the marriage. Strong repressed emotions may contribute to these symptoms. She becomes the expert on her child.

This may play into conflicts about expert advice. The division of labor in many families puts mothers and fathers in different roles vis-a-vis professionals. Usually there are practical reasons for one parent - usually the mother- to handle the child's appointments alone. In most cases, the second parent would need to take time off from work in order to attend. This may equate to lost income. If it means taking a vacation day, the family then misses out on a relaxed time together later on. This division of labor often leaves the doctor-going parent "owning" advice and diagnoses that other family members refuse to buy (Featherstone, 1980). Even parents who devise ways to share responsibility for experts and therapies may look at their professional helpers with different eyes.

Ordinary life usually offers a woman more support for child-rearing worries. Some of this support is personal, such as in many families where women cultivate ties with family and friends. They are the connectors and builders and maintainers of networks; they talk to their mothers, sisters, friends, and neighbors about the problems of

child care. Cultural norms and stereotypes may also help, by emphasizing the central role that parenting plays in their lives. A woman who worries constantly about her disabled child is following a cultural script in important ways (Featherstone, 1980). If the major crisis in a man's life concerns a child, he may feel far more isolated.

In this and many other ways parents' plans and dreams for managing their work and family roles must be altered. Less time together and more segregated roles create distance in time and space and, hence, make resolution more difficult (Sabbeth, 1984). This potential for conflict is congruent with reports of increased dissatisfaction with the marriage, less role consensus, more role tension and increased marital stress (White et al., 1984). Families governed by rigid, gender-defined roles as to who should be the primary financial provider and caretaker of children will potentially have the greatest problems with adjustment (Herz, 1980). This kind of family needs to be coached toward a more flexible view of interchanging clearly defined roles.

SELF ESTEEM

The difficulties and challenges resulting from a child's special needs can drain a parent's self-confidence. Parents often empathize with their child's pain, wishing they could suffer for the child, but often feeling helpless to do anything about it. This reaction is associated more with fathers (Shapiro, 1983) who traditionally function more in the instrumental role where they expected to solve problems. For both parents, this sense of helplessness may contribute to the loss of perceived competence and self-esteem.

While control is probably an important variable in intimate relationships, and may even be a contributing factor in the development of depression, the negative marital and family interactional sequences that arise from a depressed person's symptoms and requests for reassurance are probably also significant (Anderson, 1987). If an individual has a tendency to feel worthless and helpless, he/she is likely to be oversensitive to any messages that are perceived to reinforce these feelings. Contributing to the feelings of

inadequacy and responsibility for producing a 'less than perfect' child, parents are continually confronted by the judgments of others who may either directly or indirectly imply blame for their child's special needs. Parents feel judged and inadequate in their role as parents. This is internalized into symptoms of poor self-concept and low self-worth. Parents of children who make limited gains in their development, regardless of what interventions have been imposed, often perceive their child's lack of improvement as a direct reflection on their parenting abilities and skills.

Parental self-esteem, feelings of adequacy, and pride in being able to manage (Mattsson, 1972) contribute to their chronically ill child's well-being. Grey et al. (1980) found that in families with a diabetic child, parental self-esteem was a key factor predicting better outcomes through its association with better family functioning and child self-esteem.

COPING/ADAPTATION

The loss associated with having a less-than-perfect child leads to recurrent sorrow and grief. Families adapt to a disability by changing the ways they do things. Most adjustments make good sense, but they can strain family relationships in unexpected ways (Featherstone, 1980). The distance between parents grows as each battles fear, guilt, or fatigue, as the child's disability influences how each perceives the marriage, and as they reorganize family rituals to accommodate unusual needs. Parents may experience guilt if they believe they caused the illness or one parent may blame the other creating intense marital conflict, distancing, and sometimes, separation and divorce (Zucman, 1982). Resentments are an inevitable part of the adjustment to serious disability and they are probably an inevitable feature of any shared life (Featherstone, 1980). Parents are apt to worry about their own life-giving capability and about whether they should have more children, especially if the child is the firstborn. Parents disagree on the nature of their obligations to the disabled child. They assess his or her future options

differently and favor different plans of treatment. Mothers and fathers will probably cope somewhat differently with the emotional stress of parenthood. They may view professionals in a very different light.. The issues are momentous and parents must negotiate many conflicts in an atmosphere charged with the profoundest emotions. Each family has to decide how much they owe the handicapped child. Some mothers and fathers can resolve this question without much ill-feeling using one another as sounding boards, but standing more or less together. Other families have to negotiate at least a few important disagreements (Featherstone, 1980).

Booth (1978) has found that in the diagnosis of mental retardation, parents are given little insight into how they or the child will fare in the routine world of daily life. In this respect they differ from parents with normal children. With a child who is labeled as normal, parents can anticipate a set of developmental rules and expectations. The social meaning of having a child with special needs entails an uncertainty in trends of family interaction. The parents are faced with the task of transforming this anomalous situation into a set of meaning that can be understood by everyone as falling within the realm of normal social relations (Gallagher & Vietze, 1986). The appearance of normality in family relationships depends in part on the age of the retarded child. When children are young, mothers can readily simulate a normal-appearing round of activities. At that time, there is only a small discrepancy between the retarded child and the other children with whom the family interacts. As the children grow older, the discrepancy becomes more pronounced, and it is increasingly difficult to maintain the appearance of normal family life (Gallagher & Veitze, 1986).

Parents must learn and master knowledge and information about the disease and how to manage it. Often complex skills for home care must be learned. Sometimes parents are provided with conflicting information from physicians and other health care providers, which they must reconcile. In many cases the diagnosis may be difficult to make because many conditions are rare and physicians have had little or no experiences

with a given illness. Parents often have to struggle to find competent, reliable medical resources. This search can be exacerbated by the parents' emotional reactions when they deny and are not yet willing to accept an accurate diagnosis.

Each parent's reaction to having a child with special needs will be unique and will depend upon the supports available, the severity of the infant's handicap, and the child's prognosis. Parents' intelligence, education, health and financial state are also important. (Murphy, 1982). Parents experience periods of sadness throughout the child's life. Researchers have identified predictable stresses that many parents of a handicapped child experience during the child's lifetime (Wikler, 1981). The illness itself has a developmental course starting with the age of the child and family at illness onset and extending to the prognosis for life expectancy. In addition, the illness demands interact with the normative developmental tasks of the chronically ill child at each successive stage of development in the child's life (Patterson, 1988). Parents of a mentally retarded child may experience critical stresses during times when the child should be approaching developmental milestones like walking or talking. Parents experience stress at these times because there is a discrepancy between what most children do and the delay their child is experiencing (Meyers et al. 1985). Other periods of stress may arise when the parent faces a medical crisis, or begins to plan for the child's future.

Many families experience a developmental progression toward acceptance of a child's disability. Upon diagnosis they may experience denial, then progress to strong feelings of both guilt and anger, followed by a period of despair. Some have described the variation in coping efforts at different stages of adaptation to illness - diagnosis, living with it and terminal stages (Shapiro, 1983). Severe family stress, such as chronic illness, loss, may generate family disequilibrium that in interaction with other influences, may manifest itself in a variety of symptoms. The particular member who becomes most symptomatic and the form, severity, and chronicity of dysfunction may vary with such factors as the biological predisposition of individual members, the confluence of other

concurrent or past stresses, and family coping strategies and resources (Walsh & Anderson, 1987).

The different stages of adaptation can be put into the perspective of the grieving process which usually involves some of the stages of: shock, denial, anger, depression, blame, reorganization, and acceptance. When parents are asynchronous in going through these stages or in their coping efforts, misunderstanding and increased conflict are likely to emerge (Sabbeth, 1984). Demands include stressors (an event producing change) and strains (ongoing tension from unresolved stressors or from tension associated with role performance)(Patterson, 1988). These demands include the normative tasks associated with individual and family development. Demands also include nonnormative events such as the diagnosis of chronic illness in a child member which produces a host of hardships for the family, many of which can never be resolved and hence, create chronic strain. Families are never dealing with a single demand, rather these stressors and strains accumulate, creating a pileup of demands which interact with each other and change over time. Families can be overwhelmed and immobilized by their immediate feelings, tending to magnify the present moment, or become stuck in the past or even fixed on a moment in the future that they long for or dread. They lose the awareness that life means perpetual motion from the past and into the future with a continual transformation of familial relationships (McGoldrick, Heiman, & Carter, 1993).

Denial of the substantive impact of the birth and/or diagnosis of a handicapped child is quite common. Denial may be positive coping skill in the early stages of adjustment (Kazak & Marvin, 1984; Lazarus, 1981). It may also be a functional adaptation that serves to prevent dysfunction which individuals develop other more realistic coping skills (Rotartori, Banbury, & Fox, 1987). During the initial period, parents sense each other's vulnerability and avoid inflicting additional pain. If they blame one another for the disability, common decency usually prevents either from saying so. They may skirt around disagreements and ignore the ordinary irritations of daily life.

However serviceable this strategy is in the short turn, few couples can avoid conflict forever. Paradoxically, as the family situation improves, one or both partners may begin to speak more freely, and open conflict emerges. When the restraints are lifted, both may be appalled by the contents of Pandora's box (Featherstone, 1980).

Parents of handicapped children have many reasons for feeling angry and few arenas for expressing that anger. Some parents find that the natural irritation they feel with their disabled child - and often have successfully disguised it from themselves as well as their families - contaminates their relationship with one another. Few people admit to displacing anger, yet probably all do it. Further to this, Featherstone (1980) states the fear divides parents even before they know what is wrong. Both mother and the father notice worrisome developments. Sometimes each one agonized quietly, not daring to speak the words aloud, afraid to hear fears confirmed, reluctant to aggravate the worries of the other. Frightened people sometimes seek reassurance, and guard against confirmation of their fears by exaggerating any improvements or gains that their child makes. Many parents, especially those of children with physical disabilities, behavior disorders, and serious learning disabilities, do not realistically come to accept their child's disability and live day-by-day with the idea that they are simply inadequate to help him or her learn. Many parents of young children with disabilities also believe what is happening with their child is phase-specific, and while the developmental phase may be somewhat extended for their child, he or she will outgrow it. There is considerable social reinforcement and cultural traditions to reinforce self-defeating denial (Paul, Porter & Falk, 1993).

In the absence of a diagnosis, each parent's imagination follows its own path. As long as the truth remains in doubt, a mother and father may unconsciously balance one another - the one expressing hope while the other voices anxiety. They may switch roles periodically without ever really sharing the burden of their misery (Featherstone, 1980). Unhappiness erodes the margin in any relationship. Fear threatens communication.

Fatigue shortens nerves, reduces joy and tolerance, and drains energy needed for coping. Although not all handicapped children exhaust their parents, weariness is a common fact of life. Fatigue frays nerves, and most exhausted parents growl at one another. Fatigue exasperates existing tensions as effectively as it creates new ones. Families experience strained relationships, disagreeable routines, a sense that life takes out more than it puts back. Anger may miss its proper target and attack the relationship between husband and wife. Most parents find that school helps immensely. It gives regular relief from the child's demands, increased time for friends, work, and other interests helps mothers fight world-weariness (Featherstone, 1980).

The disproportionate allocation of parental time for a child with a disability may cause strain for both parents and other children. Finding family activities that are enjoyable and appropriate for all members may be especially difficult if the child with a disability has unusual caregiving requirements. There may also be periods of over-protection which can become a serious problem for the child who retains the capability for independence, or is not allowed to develop it. It is quite understandable that parents should be anxious about allowing any freedom or independence to a child who has sustained serious brain injury, yet this step is crucial part of the rehabilitation process (Johnson, D.A., Uttley, D., Wyke, M., 1989).

Researchers and clinicians have documented key elements in successful family coping and adaptation to a specific type of stressor such as chronic illness (Moos, 1984). Most endorse the notion that chronic illnesses become incorporated into the family system and all its inherent processes. As such, they emphasize how diseases interface with both universal and illness-specific family dynamics such as communication, problem-solving, hierarchy, role reallocation, affective involvement, information gathering, social support, utilization of community resources, mastery of home-based medical care, medical crisis planning, and maintenance of self-esteem.

A historical, systemic perspective of coping and adaptation involves deciphering how a family organized itself around past stressors and tracking the evolution of family adaptation over time. Family adaptability refers to the ability of members to change the familial power structure, role relationships, and relationship rules in response to life cycle changes resulting from developmental, structural, functional, or sociohistorical catalysts. In this respect patterns of adaptation, replication and discontinuity; shifts in relationships, and sense of competence are important considerations. McGoldrick and Walsh (1983) state that these patterns are transmitted across generations as family myths, taboos, catastrophic expectations, and belief systems.

The family as a unit or individual members, may adhere to a different set of values concerning control when dealing with a biological process as opposed to other day-to-day types of problem solving. Therefore, it is important to assess a family's basic value system first. Then, with increasingly specificity, one can assess the family's notions about control for illnesses in general, chronic and life-threatening illness, and, finally, the specific disease or disability facing the family. A family guided normally by an internal locus of control may switch to an external viewpoint when a member develops any chronic illness, or perhaps only in the case of a life-threatening disease (Rolland 1988). Such a change might occur in a family with a strong need to remain in accord with society's values, a particular ethnic background, or where the adult family members may have had specific experiences with life-threatening diseases in their family of origin.

Cohesion, the bonds or emotional unit in the family, is another resource which may emerge or become stronger as the family learns to live with the demands of the illness (Anderson et al., 1981). Cohesion, adaptability and communication are three dynamic elements characterizing the way that parents interact. (Gallagher & Veitze, 1986). Cohesion is defined as the degree of balance between the emotional bonds among family members and their individual autonomy. Cohesion can be conceptualized on a continuum, with extreme ends representing enmeshment and disengagement (Minuchin,

1974). Enmeshment or disengagement can occur between parents or between parents and other subsystems such as siblings or extended family members. Healthy family cohesion is characterized by clear boundaries and a balance of unity and individualization in relationships (Minuchin, 1974). Emotional stability within the family is achieved when the parents can view their child's disability realistically (Bennett & Algozzine, 1983).

BOUNDARIES

Salvatore Minuchin (1974) speaks of the necessity for boundaries within and around a family. He states that boundaries must be firm enough to endure over time but flexible enough to permit other relationships. Minuchin sees the creation of boundaries as the first task of a married couple. The man and the woman must free themselves from their family of origin and set up a separate space for the two of them. They must persuade their parents to see them in a new way - as a husband and a wife, rather than as a son or a daughter. They need physical and psychological space that belongs only to the two of them. Each couple must create boundaries that protect their autonomy as a couple without cutting them off from the rest of the world. Normal adults have great difficulties achieving this complex balance and the first few years of marriage are often challenging (Minuchin, 1974).

When children come, the structure changes and the couple must mark boundaries within the family as well as around it. All families have two systems, the parents' system and the children's system (Minuchin, 1974). Family members gain a lot from participating in these smaller systems as well as belonging to the larger family unity.

In order for the children's system to teach and support, it needs a measure of independence. The mother and father must acknowledge some boundaries around the sibling system. In addition to this, parents need to establish space for their own where children do not intrude. Most couples require privacy in order to negotiate conflict and,

without room to fight, they submerge their differences or perhaps detour anger and frustration through one of the children. Even in the absence of friction, they need to protect their connection to one another from the encroachments of other people (Featherstone, 1980).

Minuchin does not specifically speak to the effect of a child's disability on the organization of a family but identifies that a severely disabled child threatens important boundaries. Within the family, the severely disabled child may not fit comfortably within the other children's system or may require so much physical care from parents and occupy their thoughts so completely that he/she encroaches on their time together (Featherstone, 1980). A child's disability can cause problems which one may refer to as 'structural' problems rooted in the organization of the family and in the ways in which family members connect to one another. In addition to altering the alignments within the family, a disabled child can weaken boundaries around it, increasing the vulnerability of the family to meddling on the part of outsiders - experts, relatives, and nonprofessional helpers can destroy the external boundaries.

The presence of a child with disability can change the structure of the family in a number of ways. In addition to weakening the boundaries that protect the autonomy of different systems within the family, it makes the family more vulnerable to the intrusions of outsiders, particularly doctors and other professionals. A child's disability usually puts a family in touch with a variety of professionals and other experts. The nature and the extent of these contacts varies widely from family to family.

FINANCES AND CAREER

There is usually a very large financial burden associated with the care of a chronically ill child incurred from the expenses of surgeries, drugs, equipment, supplies, doctor bills, travel, special schools, and so on. Meeting these financial demands creates worry and tension, not only for parents, but often for the whole family (White et al, 1984). The work lives of parents must often be rearranged to accommodate the needs of a chronically ill child. Parents may seek additional jobs or work longer hours to pay the bills. One parent, usually the mother, may terminate employment or even a career to stay home and care for the child, especially when there are no alternate sources of care or when there is considerable involvement with medical services or treatments which require numerous appointments or visits to hospitals. This loss of income will mean that the wage earning parent may have to work more hours to earn enough to support the family, especially given the added financial burden imposed by the needs of the chronically ill child. Parents may decide to turn down job promotions requiring relocation because they choose to stay close to specialized treatment centre for their child or the perceived difficulty in accessing similar services. A family may also be forced to move in order to access services for their child.

Mothers who may feel responsible for the child's condition, typically exercise their strong commitment to providing the best possible care for the child at the expense of their career aspirations (Hirst, 1985). Studies of families of handicapped children find that mothers spend large amounts of time on child care and household tasks (Breslaum, 1983) and tend to work in the labor force less than mothers of nonhandicapped children (Baldwin, 1985). Families with reduced career opportunities obviously have lower incomes than other families. Added to this is the expense of caring for a handicapped child.

This is exemplified in a British study, (Baldwin, 1985), which compared earnings and expenses of some 400 two-parent, special needs families with the income and

expenditures of about 600 control families. These findings suggest that families with disabled children, particularly those with severely handicapped children, will fare worse economically than other families.

Lower income families have a particularly difficult time managing a child with chronic illness. They struggle just to cope with the basic needs for food, clothing, shelter, and so on, and have a harder time attending to the psychological needs of family members. Furthermore, caregivers accord poor families less respect and these parents often do not know how to assert their rights (Zucman, 1882). Financially disadvantaged families often fail to get good medical care. Some children get limited technical assistance in hospital, clinic, or classroom.

The financial impact of caring for a family member with a handicap is likely to be negative for the whole lifespan of the child. Whether the disabled person requires unusual medical attention and materials or simply represents a high degree of dependency, the costs do not end with adulthood. The extent of the disabling condition determines, to some extent, the degree of financial impact, with more severely disabling conditions increasing the likelihood that a child will be the parent's financial and emotional responsibility for the remainder of their lives.

The marital relationships for poor couples is usually stressed more because of the multiple pressures in their lives. Often a disproportionate share of the family's resources are devoted to the needs of the chronically ill child and trying to attend simultaneously to multiple family needs in the face of the uncertain course of the illness is a challenge to family equilibrium. A history of chronic, stress-creating family problems makes management of illness harder. In many ways chronic illness lowers the family's threshold of tolerance for other problems. The challenge to the maintenance of the family as a unit sometimes does not work out, and the unit dissolves. An unstable family composition usually makes managing the chronic illness more difficult (White et al., 1984).

CULTURE

Cultural groups vary greatly in their breakdown of life cycle stages and definitions of the tasks at each stage, and the family life cycle patterns of groups differ as well (McGoldrick, 1988). Cultural attitudes towards children with special needs may influence a parents willingness to access services or follow up with professional recommendations. In addition to this, language barriers may result in further confusion and communication breakdowns between families and professionals. Conflict over professional advice may have cultural roots as husband and wife interpret the meaning of their child's special need from a cultural perspective. The influence of extended family, with their values and belief systems about children with special needs and their treatment there of, may create either a healthy support system for parents or an arena of additional conflict and stress.

Cultural norms may influence women to seek and accept help more readily than men do. Having learned to speak of their feelings, to admit unhappiness, and to accept sympathy and encouragement, women may form a strong, if temporary, bond with a doctor or therapist. A man who fights a losing battle with confusion and despair longs for care and comfort. He may envy his wife's ability to solicit support and may also feel jealous of the person on whom she depends. When a husband sees his wife beginning to emerge from her cocoon of despair, ready to join a world beyond the family, he may have mixed feelings. He is glad that she is trying to heal herself and help their child, but he may feel somewhat left out and left behind. Loneliness and jealousy may impel him to attack his wife's support system in one way or another (Featherstone, 1980).

TRANSITIONS

All transitions inherently involve the basic processes of initiation and termination. Arrivals, departures, and losses are common life events, during which there is an undercurrent of preoccupation with death, finiteness (Levingson, 1978), and

vulnerability. Chronic and life-threatening illness precipitates the danger of losing an identity of the family. It forces the family into a transition in which one of the family's main tasks is to accommodate the anticipation of further loss and possible untimely death. When the onset of a chronic illness coincides with a transition in the individual or family life cycle, one might expect that issues related to previous, current, and anticipated loss will be magnified.

Transition periods are often characterized by upheaval, rethinking of prior commitments, and openness to change. As a result, at those times, there is a greater risk for the illness to become unnecessarily embedded in family life or inappropriately ignored when planning for the next developmental period. During a transition period the very process of loosening prior commitment creates a contest for family rules regarding loyalty through sacrifice and caretaking to take over. Feelings of indecision about one's future can be resolved by excessive focus on a family member's physical problems, which can be a major precursor of family dysfunction in the context of chronic disease.

SUPPORT SYSTEMS

Parents of a handicapped child will normally find themselves bombarded with advice and suggestions from friends, relatives, educators, psychologists, therapists, social workers, and medical doctors. The influence of experts extends into the home as well. Physical therapists design programs for parents to carry out; occupational therapists suggest better ways to feed, dress, and bathe the child; doctors perform corrective surgery; nurses describe a regimen of postoperative care which parents implement; and teachers try out educational strategies in the classroom and explain the importance of consistent home follow-up (Featherstone, 1980). These efforts help the child develop and may lessen the family's isolation. Such efforts speak of society's dawning commitment to the handicapped and encourage our hopes for the growth of a tolerant, concerned

community. They can, however, also reduce a family's independence and autonomy. Medicine has done a great deal for the disabled, but a medical model - any model based on hierarchies of clients and expert professionals - has serious limitations. These limitations matter most at the points where problems become human, not technical (Featherstone, 1980).

Community attitudes may be powerful mediators of coping strategies and concomitant levels of stress in these families (Mercer, 1973). The impact of a label may be augmented or de-emphasized by the quality of formal and informal support. Compassion or perceived stigmatization among interacting facets of the social network may make the difference between functional and dysfunctional adjustment to the realities of raising a child with a handicap.

The family's privacy is invaded by the constant need for service. Professionals probe into many domains of family life with the intent of helping, but at the same time they are often judging and trying to change the family. Sometimes professional helpers are insensitive to the emotional demands on these families, and this may be related to the professional's unwillingness to process his or her own emotional reactions. Friends, relatives and even casual passers-by offer tips and information. The difficulties resulting from a child's disability can drain a parent's self-confidence, even friendly suggestions can seem overwhelming. Such intrusion goes beyond advice. A family may change the entire composition of its household in order to meet the handicapped child's needs (Featherstone, 1980).

The tasks associated with caring for a chronically ill child often consume an inordinate amount of parents' time and physical energy. This intense and chronic demand for care is aggravated by the difficulty of finding respite care. Parents have difficulty trusting others to care for their child because of the vulnerability of the child. A minority of families attempt to reallocate the burdens of care by adding a new person to the household. Relatives often are afraid to care for children who look or act differently or

appear fragile and vulnerable. Grandparents are often a source of continued sadness and tension since they may find it harder to come to terms with their loss than the parents (Johnson, Uttley, & Wyke, 1989). Parents find that time and energy for self, spouse, and other children are often sacrificed.

Many parents believe that neighbors, friends, and relatives withdraw from them because of their special circumstances. Some families may reject offers of help or friendship because they believe either that such gestures are insincere or that they would not be able to reciprocate. Finally, the practical requirement of handicapped children, such as special transportation and child care needs, adversely affect family members integration in the community. Developing a support network of understanding friends and relatives who listen is an important strategy for reducing chronic stress (Levine & Ebert, 1983). To maintain a balanced perspective and to avoid parent burnout, parents must learn to make time for themselves, and respite is an important priority for families of the handicapped.

Social support networks are hypothesized to buffer individuals from the potentially depleting effects (physically and emotionally) of normative and nonnormative stress (Dunst, Trivette, & Cross, 1986). There is extensive literature describing the positive relation between social support and parental well-being (Beckman, 1991; Dunst & Trivette, 1990), diminished maternal depression and an enhanced sense of parental competence (Gowen et al., 1989).

COMMUNICATION

Communication can be described as the process by which information is transmitted in families. Important aspects of family communication skills are effective listening, sending clear messages, and providing feedback. Some families avoid communication on issues related to retardation (Gallagher & Veitze, 1986) and other issues pertaining to a child's special needs. Parents may avoid asking questions of each

other that they do not want to hear the answers to. There is also a tendency to avoid discussion on any issue which may be emotional and difficult to talk about. When such discussion is avoided, the feelings associated with the topic may be 'stuffed' only to present at another time, perhaps under less desirable circumstances.

It is possible that spouses value certain outcomes in their marriage but may face personal, relational, or environmental constraints that hamper their ability to realize these outcomes. Spouses may value open and disclosive communication patterns in their relationship but may lack confidence in their ability to develop more effective communication exchanges. Couples need to confront barriers and develop the skills and resources necessary to realize their values for marriage (Bowen, 1991).

A communication style that allows for the open expression of feeling is especially adaptive in these families who experience powerful, often conflicting emotions.

CHAPTER III - GOALS AND OBJECTIVES

The demands for caring for their ill child frequently create or exacerbate conflict in the marital relationship. Lack of consensus about how to manage the child, other family demands, goals for the future and so on, may create tension and conflict which become chronic and unresolved (Chilman et. al., 1988). When both parents are able to integrate their feelings about their child's handicap, they can support each other in the recurring crises that will arise throughout the child's development (Meyers et al. 1985).

The impact of illness, the stress of caregiving roles, combined with pre-existing and/or concurrent stresses all should be addressed in designing clinical care for patients and families. In order to achieve the goal of assisting couples to explore the impact that having a child with special needs has on their relationship and offer ways to enhance their marital relationship, the following objectives will be utilized:

A. Develop a better understanding of relationship issues and dynamics which either facilitate or restrict opportunities to achieve satisfying marital relationships and how having a child with special needs plays in the scenario. As part of this objective, 'typical' relationship issues will be explored, as will be how those issues are affected by having a child with special needs, and identifying issues specific to families of children with special needs. Systems theory and theories relevant to family development, couples, and ambiguous loss will provide the framework for achieving this objective.

B. Assist participants to explore coping and problem solving strategies. Parents will consider current communication patterns and identify their current roles. Using a problem solving model, parents will identify a process to constructively confront crisis situations. Participants will also develop their personalized list of coping strategies. In addition to the problem solving model, this objective is also most significantly influenced by stress management principles.

C. Identify support systems. Group participants will have the opportunity to design a model of support for themselves as individuals and as couples. Guiding this goal are the principles of systems theory, and theories influencing family development and family therapy.

D. Identify how the child with special needs impacts other family members.

Many parents expressed concern over wanting to understand how their other children were effected by having a brother or sister with special needs. Looking at the variables of boundaries, gender issues, coping/adapting, and roles, the group will explore the issues from a systems perspective. Other influencing theories pertaining to this objective will be the theories of family therapy, bereavement and adjustment, and ambiguous lost.

E. Help spouses to better understand the dynamics of marital interaction, to gain greater self-awareness and to develop concrete skills for relational enhancement.

Looking at the variables of gender, roles, boundaries, communication, and adjustment, participants will be encouraged to identify barriers to relationship growth, thereby fostering a more productive partnership, marital well-being and growth. Participants will be able to appreciate individual differences in marital values and goals within and between couples. Theories relating to the couple and to family therapy will provide the basis for achieving this objective.

F. Understand the adjustment process. Group participants will be presented information on the different stages of the adjustment process and will have the opportunity to identify how they move through the process and appreciate that they and their partner can be a different stage of adjustment on the same issue.

CHAPTER IV - SOLUTION STRATEGY

I THEORETICAL PERSPECTIVES

SYSTEMS THEORY

Brammer (1979) defines stress as a condition characterized by physiological tension and a persistent conflict of choices that pressure the person to reduce the tension and achieve equilibrium. Crnic, Friedrich and Greenburg (1983) report that the degree of stress perceived by family members is mediated by coping skills that are mediated in turn by ecological systems. Ecological systems composed of an individual, that individual's family, peer group, and social institution have a powerful effect on his or her ability to cope during any stressful situation. Coping skills that determine the level of stress experienced by the individual are influenced by feelings of helplessness or of being in control; perceptions of support available from social networks; parental health, energy, and morale; parental problem-solving skills; and practical resources such as financial resources.

The McMaster model is built on systems theory and is based on the assumptions that the parts of the family are interrelated: one part of the family cannot be understood in isolation from the rest of the system; family functioning cannot be fully understood by simply understanding each of the parts; and a family's structure and organization are important factors determining the behavior of family members: and transactional patterns of the family system are among the more important variables that shape the behavior of family members (Epstein, Bishop, et al, 1993).

This model explores six dimensions including problem solving, communication, roles, affective responsiveness, affective involvement, and behavior control. The application of the McMaster model is more conceptually based than skill-oriented. The goals of the program are to:

- Foster more productive partnership, foster marital well-being and growth
- Understand contemporary patterns and trends in marital and family relationships

- *Examine their values and goals for marriage and how these values and goals may have changed over the marital career.*
- *Better appreciate individual differences in marital values and goals within and between couples.*
- *Examine present behavior in marriage in the context of their individual and collective values and goals.*
- *Identify personal, relational and environmental resources and barriers to realizing defined individual and collective values and goals for the marital relationship in behavior.*
- *Develop an action plan for the marital relationship toward a higher level of marital teamwork and relationship satisfaction.*

PROBLEM SOLVING

When the usual problem-solving techniques do not resolve the problems associated with having a handicapped child in the family, disequilibrium may result. Aguilera and Messick (1978) believe that the individual must either solve the problem or adapt to its presence. Leaving the problem unsolved leads to inner tension, signs of anxiety, disorganization of function and a protracted period of emotional upset. Most people see problems in their marriage as a sign of personal failure. A combination of pride and personal loyalty may prevent one from sharing concerns about a deteriorating relationship and from analyzing points of friction (Featherstone, 1980). Some parents will find solutions more easily than others.

Aguilera and Messick (1978) have developed a systematic, short-term, problem-solving approach to crisis intervention that focuses on solving the immediate problem. They believe that whenever a stressful event occurs, there are certain balancing factors that can bring about a return to equilibrium. These factors are: the realistic perception of the event; the available situation supports; and adequate coping mechanisms.

Aguilera and Messick (1978) state that if the event is perceived realistically, there will be recognition of the relationship between the event and feelings of stress. In other words, what does the event mean to the individual? How is it going to affect his future? They also believe that, by nature, humans are social and dependent upon others in their environment to supply him or her with reflected appraisals of their own intrinsic and extrinsic values. Situation supports mean those persons who are available in the environment who can be depended upon to help solve the problem.

The third component of this approach is to develop adequate coping mechanisms. These are described as tension-reducing mechanisms and coping methods people use to relieve their tensions and anxiety when faced with a problem.

Problem solving ability and conflict resolution skills are important resources for families who have multi-issues and competing demands to deal with (Borrows et al., 1985). Such skills help maintain a lower level of conflict which contributes to better outcomes. McCubbin et al, (1983) found that the coping patterns of maintaining family cooperation and unity, and maintaining the parents' psychological well-being were associated with better health outcomes in the child.

FAMILY DEVELOPMENT

There are a variety of theories about the various stages of family development. Most describe the couple during their courtship, coming together in marriage, having children, followed by the developmental stages of their children until such time as the children leave and the couple grows old together. Duvall (1977) and Carter and McGoldrick (1980) describe the following family life cycle stages :

- the unattached young adult
- the newly married couple
- the family with young children
- the family with adolescents

- the family launching children and moving
- the family in later life.

There are many different things that motivate people to have children. A couple may want to emulate their own parents, may desire to compete with their own parents or may want to prove their sexual adequacy by producing a child. They may feel destined or pressured by their ethnic or religious beliefs to bring forth a child to perpetuate the race, family name, or religion. Some people may be trying to give meaning to lives that seem empty and without purpose or may be seeking a form of immortality. Conversely, men and women may simply wish to nurture, to shape, guide, and cherish a child.

For whatever reason they choose to do so, change is high at the time of having a baby. For the couple who are having their first child there are adaptations to the new member. These may include middle of the night feedings, the mother having to leave her job, a lack of time alone for the couple, extra financial burdens, and a chaotic life. The baby's presence has, however, increased the sense of bonding between the husband and wife (Olson, 1993).

From this stage the normal process is for a family to move into a phase of stabilization as they experience changes. For the family of a child with special needs this stage is often tenuous and more difficult to establish. If the child has been diagnosed with a special need at birth the family are more likely to follow a closer pattern of establishing daily routines and normalizing around the needs of the child. If the child is diagnosed at a later date, the family may return to the chaotic elements of adaptation to a new series of developments. Farber (1959) defined the character of the crisis faced by families with mentally retarded children as an arrest in the family life cycle, whereby family development is slowed and family roles are thrown out of synchronization with the cohort of families who would ordinarily define the character of family development. The hypothesis of family cycle arrest also proposes that, regardless of birth order, the

social role of the retarded child eventually shifts to that of the youngest child (Farber, 1959).

A central concept for both family and individual development is that of the life cycle. The notion of cycle suggests an underlying order of the life course where individual, family, or illness uniquely occurs within a context of a basic sequence or unfolding. A second key concept is that of the human life structure. The primary components of life structure are a person's/family's reciprocal relationship with various others in the broader ecosystem. The life structure forms a boundary between the individual/family and the environment and it both governs and mediates the transactions between them (Chilman et al., 1988).

Illness, the individual, and family development have in common the notion of eras marked by the alteration of life-structure -building/maintaining and life-structure-changing (transitional) periods linking developmental eras. Transition periods are potentially the most vulnerable because previous individual, family, and illness life structures are reappraised in the face of new developmental tasks that may require discontinuous change rather than minor alterations (Hoffman, 1980). In the face of chronic disease a family will have to deal with the developmental demands presented by the illness without family members sacrificing their own or the family's development as a system. It is vital to understand what life plans the family or individual members had to cancel, postpone, or alter as a result of the diagnosis. What plans are most and least affected? Under what conditions will they resume plans put on hold or address future developmental tasks? Working with families of children with special needs requires helping individuals to resolve feelings of guilt, over-responsibility, and hopelessness, and helping to locate resources internal and external to families so as to give them more freedom both to pursue their own goals and provide needed care for the ill member (Rolland, 1988).

From a systems viewpoint it is important to know the phase of the family life cycle and the stage of individual developmental of all family members at the time of a chronic illness diagnosis. This is important information as the chronic disease in one family member can profoundly affect developmental goals of another member. In addition to this, family members frequently do not adapt equally to chronic illness. Each family member's ability to adapt and the rate at which he or she does so is directly related to each individuals own developmental stage and his or her role in the family (Ireys & Burr, 1984).

Although individual family members can hold different beliefs, from a family systems perspective, the values operating at the level of the whole family may be the most significant. A family's sense of mastery over an illness and a family's beliefs about the cause of an illness will be the key elements in determining how the family will cope and adjust to the challenges of having a family member with special needs.

BEREAVEMENT/ADJUSTMENT

Coping with chronic illness and death are normally considered anticipated tasks in late adulthood. Illness and loss that occur earlier are out of phase and tend to be developmentally more disruptive (Herz,1980). As untimely events, chronic diseases can severely disrupt the usual sense of continuity and rhythm of the life cycle. Chronic diseases that occur in the child rearing period can be most devastating because of their potential impact on family financial and child rearing responsibilities (Herz,1980) .

Adjustment may proceed in stages, often interrupted by episodes of fresh grief and anxiety. There may be times when the parents feel a sense of rejection for the damaged child and question whether they can carry on caring for him or her; yet often if one gently raises the suggestion of residential care or even of respite care, they may be angry that one doubts their commitment. Perhaps the apparent rejection is again a means of distancing themselves from the pain of knowing that this damaged person is their own

offspring; it would be easier to care for such a person if there were not that sense of personal loss.

A well recognized form of rejection or avoidance is seen in the parent who becomes an active campaigner for the relevant voluntary organization, develops an expertise in technological aids for the handicapped, or engages diligently in legal battles to obtain compensation. All of these activities are of course valuable both for the child and for society, but they can at the same time be a means of spending as little time as possible with the child who is the cause of grief (Johnson, D.A., Uttley, D., Wyke, M., 1989). This may in turn lead to resentment on the part of the other parent if they do not share the same aims.

Mandell and Fiscus (1981) acknowledge the importance of grieving the loss of not having a normal, healthy child. They suggest a five-stage process for both professionals and society to acknowledge:

1. Denial

Parents often refuse to believe the existence of a handicap, the permanence of it or its impact on the life of the entire family.

2. Guilt

Parental guilt is manifested in one of three ways. The least common is attaching the cause of the child's handicap to some specific past action. The second form of guilt is the belief that "bad thing happen to bad people - therefore, I am bad." The third form - the most frequently found and the most difficult to deal with - is the belief that the impaired child is a just punishment for something the parent has done.

3. Depression

Depression has been described as anger turned inward. Parents punish themselves because they can not do what they want to do - make the child nonhandicapped.

4. Anger

Anger occurs on two levels. The first is often expressed as "Why me?" The other is usually unspoken and frequently displaced onto the spouse, a sibling, or a professional.. This silent anger is actually hatred for the handicapped child.

5. Bargaining

The last stage is bargaining with science, with God, or with anyone to cure the child. It is the "last ditch" attempt by parents to change their circumstances.

Not all parents go through all stages, and the intensity and duration of each stage varies from parent to parent. Acceptance is not a static phase. It has to change and develop as the handicapped child grows, reaches puberty, and becomes an adult. Life does not become easier for the parents, whatever the nature of the disability (Johnson, Uttley, & Wyke, 1989). The parents not only have to work out their own acceptance, but also that of grandparents and siblings.

Hoff (1984) points out that parents of developmentally disabled or handicapped children can experience crisis at many different times, such as:

- when the child is born.
- when the child enters and does not succeed in a normal classroom.
- when the child develops behavior problems peculiar to his or her handicap.
- when the child becomes an adult and requires the same care as a child.
- when the child becomes an intolerable burden and parents lack the resources to care for him or her.
- when it is necessary to institutionalize the child.
- when institutionalization is indicated and parents cannot go through with it out of misplaced guilt and a sense of total responsibility.

- when the child is rejected by society and parents are reminded once again of their failure to perform as expected.

Darling (1979) identified three types of long-term adaptive styles in families with a chronically ill or disabled child: the normalizing, crusading, and resignation styles. Darling believes that most successful parents adapt to their child's condition by creating a near-normal life for themselves and the child. Normalizing adaptation is possible only where the needed medical and other services have been found. It can be thought of as embracing the cognitive, emotional, and social processes for second-order change. When a child's difficulties are recognized and supportive help is available that does not dispel all anxiety as chronic conditions do not disappear with remediation, although they may become more manageable. Each new situation, each new stage of life, presents a multitude of unknowns to be dealt with (Stewart, 1986). As each new situation of development presents itself the parents again need to draw on coping strategies and resources. Parents support each other in managing their chronic sadness and occasional anger or guilt feelings, so that they can freely encourage their child's optimal independence, relatedness, self-esteem and self-direction. The child's condition often requires a disproportionate amount of emotional investment by the parents, as well as, time and finances. This leaves less for the other children who may feel emotionally neglected. In the social area, the family strengthens or begins to build a network of supportive neighbors and friends. They seek and accept financial or child care help from relatives as needed. Loving grandparents can support and enhance the emotional resources of both child and parents and can help keep hope alive. Families who adapt the normalizing style have a sense of control over their lives much as parents with healthy children do. They make second-order changes through these cognitive, emotional, and social processes and achieve a new family paradigm (Germain, 1991). The transformation involves reorganizing family roles, tasks, and so on. This adaptive achievement allows the needs of all family members to be met at an optimal level despite

the many demands made by the child's condition, and allows the illness or disability to be slowly integrated into the way the family views itself and its world.

In the crusading style, parents become assertive and effective advocates and lobbyists for services for their children and themselves. These are empowering activities that give additional meaning to the parents' lives. Probably many normalizing parents incorporate elements of the crusading style into their new paradigm and its worldview.

Darling believes that only a few parents adopt the style of resignation. These parents become fatalistic and resign themselves to their powerlessness. Many develop neurotic symptoms, and some may fail to cope effectively and break down. In most cases these families are socially isolated and do not become integrated into self help and voluntary associations. They fail to integrate the illness or disability adaptively into their lives and worldview: the developmental needs of some or all family members are not met (Germain, 1991).

Relationships change as time passes. An intimate relationship is able to balance between too much change and too little change. Too much change leads to a lack of predictability and chaos, whereas too little change leads to too much predictability and rigidity. An intimate relationship is able to change when appropriate and staying unbalanced too long can create problems in an intimate relationship (Walsh, 1993).

AMBIGUOUS LOSS

Caregivers and their families are burdened less by the severity of an illness than by the uncertainty it causes. A high degree of uncertainty prevents families from defining their situation and moving on. Defining the situation is the cognitive prerequisite for coping and managing. Family processes seize, the family is restrained and immobilized. So far research supports the hypothesis that boundary ambiguity causes depression in caregivers, as well as, conflict in caregiving family systems (Boss & Greenberg, 1984).

Boundary ambiguity is defined as not knowing who is in or out of the family system. Indicators are primarily perceptual. It is not just who is physically present in a household, but who is psychologically present or absent as well. Boundary ambiguity is a perceptual variable that helps to explain why some families successfully manage to live with chronic unclear loss while others do not.

The symbolic interactionists perspective provides a more optimistic outlook for care-giving families. Rather than seeing the future as predetermined and hopeless, families can at least be in charge of their definitions of the situation. While some see having a child with special needs as punishment from God - others see it as a challenge. Symbolic reconstruction or reframing, is functional because it lowers a caregiver's stress when the situational is irreparable, such as in the case where a child's recovery is impossible.

Families, no matter how strong they are, cannot change the reality of handicaps, syndromes or diseases, but they can hopefully shift in the way their family is constructed. Roles can be reassigned to others, celebrations and rituals can be adapted to include the child with special needs, and the meaning that individuals and the family as a collective give to their situation can be adapted over time as the illness progresses. Individual and familial appraisals influence how they change or resist changing. When perceptions are dissonant between family members, conflict is high, the primary caregiver's depression is high, and change is blocked (Boss & Greenberg, 1984). Shared meaning of what is happening changes constantly with long-term illness and this stresses the family in new ways. Family members can avoid crisis by talking together regularly about their definitions of the situation and should be encouraged to talk about their perceptions of what is happening even though they may disagree. How do they see their roles and tasks changing during the process of coping? How does this process influence behaviors across the generations in their family? Are there gender differences in how the situation of illness is defined? Is there any information the family needs that would lower their

stress? Overall, this validates the individual's loss while supporting reconstruction of family life. Boss (1988) reports that caregiving families reported that the most helpful feature of this type of intervention was being able to come together in one room to talk about the illness, often a topic previously avoided. The caregiving family's collective meaning about the effecting condition is clarified only after there is a process of verbal interaction among members of the whole unit regarding their loss. This happens best when family members sit together in a room and talk. While the caregiver's definition of the situation is valued, it might disagree with physical reality (Boss, 1988). Therefore, both objective and subjective measures of boundary ambiguity are important.

COUPLE COUNSELING

Any child complicates his or her parents' relationship in practical, as well as, symbolic ways. From the moment of conception, each person's ties to the other tangle with duties to their offspring. Someone must perform basic household and child-care routines - usually either the father or the mother. Much of what parents do for their children they also do for each other. They juggle responsibilities searching for an arrangement that would allow both to keep their sanity (Featherstone, 1980).

Sometimes mothers and fathers of exceptional children face peculiar difficulties because they are divided internally, as well as, between themselves. Each partner may feel deeply ambivalent about the child, the future, the advice of experts, and many other problems. Ambivalence is, however, confusing and upsetting. Sometimes mixed with feelings that get put aside, only to be expressed in a conflict between husband and wife. Either partner's ambivalence raises the emotional stakes of marital conflict. Mixed feelings prevent both husband and wife from listening to one another's ideas, and from hearing the loneliness and the desperation that the other is really feeling. Shared, but unexpressed, ambivalence can also limit emotional options, prolonging or intensifying a miserable stand-off (Featherstone, 1980). As the family comes to terms with what the

child's needs will mean to the family they will have to re-establish their roles as parents and as life partners. It is expected that family systems will change in response to this type of a crisis. The impact of such a crisis will be determined by the connectedness of the couple.

At certain points many mothers and fathers find family life constricting. Any reasonable person regrets the loss of freedom occasionally. Some people long for a vacation from emotional responsibility, from the worry about children's happiness and well-being. Others remember with nostalgia a period of greater flexibility. A child places new restrictions on work, play, sleep, and sex. Parents may miss economic independence - the freedom to quit a disagreeable job, to try a new career or to defy a stupid rule (Featherstone, 1980). With luck, the pleasures of parenthood outweigh the loss of liberty. A child's disability can shift this balance as concerns for the future weigh heavily on both parents.

Not every one confuses the difficulties of child care with those of maintaining a marriage. Some parents never imagine that they might escape exhaustion and despair by leaving their family behind. Some people threaten to leave in an effort to communicate the depth of their despair or to short-circuit their own fears of being abandoned. Most keep their fantasies private (Featherstone, 1980). The open road loses its charm as life improves at home. Still, many mothers and fathers need help in learning to disengage their feelings about the marriage from the child and his or her disabilities.

From the perspective of marital enrichment, the value-based approach to the definition and conceptualization of marital satisfaction is rich in its implication. First it is important to help spouses better understand their values and goals regarding marriage. It is particularly important to help them identify where they have value differences or incongruities with one another. The husband and wife may have differing views toward the sharing of household tasks and responsibilities. It is likely that such value discrepancies between spouses that are not recognized or discussed, but when the value in

question is more important to one spouse than the other, it can create an undercurrent of tension and conflict in the marriage. Such a situation negatively affects the level of marital satisfaction experienced by the spouse by decreasing the level of positive emotions and /or by increasing the level of negative emotion toward the other spouse or toward the relationship or marriage in general. Value congruity between spouse across those value domains that are defined as important by one or both spouses is likely to facilitate exchanges in marriage that are defined as rewarding, as well as, equitable (Bowen, 1991).

Bowen (1991) states that it is valuable to have spouses compare values and goals for marriage with their actual behavior and patterns of marital interaction. This focus on gaps between marital related values and behaviors would assist spouses in better understanding their current level of satisfaction with the marriage and in identifying aspects of their relationship that they would like to promote or change. This exercise would be especially valuable if spouses were able to jointly examine their ability to behaviorally realize their individual and collective marital related goals.

Marital enrichment programs vary in structure and content but are all broadly based on the assumption that marriage is a dynamic and growth oriented process. The underlying goal is to help couples achieve more satisfying and meaningful relationships; mutually supportive relationships that foster the ability of spouses to better realize their individual and collective potentials and ambitions. Content and activities in these programs are geared generally toward helping spouses better understand the dynamics of marital interaction, gain greater self-awareness, and develop concrete skills for problem solving and relational enhancement (Giblin, 1986). The marital relationship is enhanced by couples who take time for themselves even in the face of many demands (Patterson, & McCubbin, 1983). A qualitative marital relationship characterized by mutual support, intimacy, satisfaction, and shared goals is a key resource in effective family functioning associated with better adaptation to chronic illness demands (Foster & Berger, 1983).

One way to bring a husband and wife closer together is to equalize some of their opportunities. In many traditionally organized families this means providing men with more support - from friends, family members, and professionals - and with more chances for constructive involvement with the child, while allowing mothers an arena for achievement outside the family. Changes of this sort bring the paths of husband and wife somewhat closer together and help them to cope in more complimentary ways (Featherstone, 1980).

FAMILY THERAPY

As characterized by Minuchin and his colleagues in the classical formulation of the psychosomatic family, four family characteristics are crucial:

- 1) enmeshment and overinvolvement of family members as seen in poorly differentiated subsystem boundaries;
- 2) over protection of each family member which interferes with the unfolding of the separation individuation process;
- 3) rigid transactional patterns aimed at maintaining the status quo at all costs;
- 4) a lack of conflict resolution in which conflicts are either denied or avoided.

Such a family according to the Minuchin et al. (1974), presents itself to the outside world as a conflict-free unit whose only concern is the presence of a chronic illness in one of its members.

In their study, Craig Everett and Sandra Volgy (1987) determined that the clinical goal for family therapy was to increase the abilities of all family members to own or accept potentially negative aspects of themselves and thus to be able to move toward interacting as "whole" persons with one another. This involves the clinical task of working through the interpersonal distortions and reducing the systemic projective

identification process, moving their interactional patterns and experiences within the system to a more openly affiliative level. The oppositional and stereotypical role behaviors of all the members must be reduced. External boundaries for both the nuclear and intergenerational systems must be re-established. This involves the clinical task of closing the external boundaries around the nuclear system which will have the effect of reducing the vertical loyalties for both parents and resetting the internal nuclear boundaries for the spousal, parent-child, and siblings subsystems. In addition to this, the internal boundaries between the spousal and the sibling subsystems need to be closed to limit the reciprocal intrusiveness of the children and the parents with one another. Within the family, it is necessary to guard some private space for the mother and father, so that they can solve private disputes and reinforce the ties that bind them to one another. This will result in a clearer alliance between the two parents.

Common to most contemporary theoretical frameworks of family adaptation is the perspective that families, as a system, have to change in response to normative transitions and unpredictable events while preserving their integrity and organizational coherence (Krauss & Jacobs, 1990). Several models of family adaptation have been formulated since the early 1980s. They include the Double ABCX Model of Adjustment and Adaptation (McCubbin & Patterson, 1983), the Stress-Adaptation Model (Farran, Metzger, & Sparling, 1986), and the Model of Stress, Coping, and Family Ecology (Crnic et al., 1983). While the three models differ in their emphases, they converge in their identification of determinants of adaptation, including characteristics of the stressful event, available internal and external resources, the family's attribution of meaning to the event, and interactions among the various ecological contexts in which the family operates.

The presence, realization and impact of a handicapping condition is usually felt by all members of the family because of the emotional, social, educational, and economic demands placed on them. These obligations make families of handicapped children

particularly vulnerable to stress (Stewart, 1986). When parents develop and maintain cooperativeness and shared responsibility and when they work to maintain an atmosphere of normalcy by getting out and doing things as a family, children do better (Patterson, 1985).

Walsh and Anderson (1987) identify that at a minimum, family intervention priorities should include: the reduction of the stressful impact of chronic disorders on the family; the provision of information about the medical/psychiatric condition, patient abilities and limitations, and prognosis; concrete guidelines for stress reduction and problem-solving; and linkage to supplementary services to support the efforts of families to maintain their patient members in the community.

II PROGRAM DESIGN CONSIDERATIONS

The bulk of investigations concerning family factors and chronic illness imply either case study or correctional designs. Neither of these approaches allows for causal interpretations about the interactive effects between illness and family factors (Steinglass & Horan, 1987) .

Chronic medical conditions present unique challenges to family therapists in the design of interventions that respect not only the psychological health of the family, but also ensure that the patient's medical treatment is being adequately supported. Steinglass, Gonzalez, Dosovitz & Reiss, (1982) and Gonzalez, Steinglass & Reiss (1986) present design and implementation of a short-term multiple-family discussion group approach that borrows heavily from principles unitized in psychoeducational programs for chronic psychiatric disorders. The group is an eight-session treatment in which four to six families with a chronically ill member meet weekly to discuss issues of shared relevance. Three major components - educational, family issues (problem-solving), and feelings (affects) - are addressed by the families in an effort to define the aspects of family life

that seem generic to the chronic illness issue and the coping styles that families find most helpful in dealing with the stresses associated with the illness (Steinglass & Horan, 1987).

Often operating within a systems perspective, these programs look at the interface between family behavior and illness characteristics and ask questions about how family illness variables mutually reinforce one another as the illness moves into its chronic phase. Often the questions being asked are to determine what aspects of family behavior serve to maintain the chronicity of medical illnesses, and vice versa. Steinglass and Horan (1987) identify that specific family patterns seem to be associated with increased chronicity of medical illness. These systemic implications are such family factors as: exclusionary coalitions between the individual with special needs and select family members; stability of marital dyad; family communication patterns; and quality of family daily routines.

Multiple family groups are particularly relevant with this population since they can provide a vital network function for families who have common problems, who have been isolated, or who have been stigmatized by their child's chronic problems. Multiple family groups give parents, siblings, and spouses the opportunity to share similar experiences, provide mutual ongoing support, and expand one another's repertoire for crisis management and reduction of stress and conflict (Walsh & Anderson, 1987). Self-help groups provide support and information along with the opportunity to perform a helping role in relation to similar families struggling with similar problems. These groups can develop valuable advocacy functions to increase the contribution of resources.

According to Stewart (1986) group counseling has disadvantages (such as the demand it places on the skills and competencies of the counselor), but it can be effective for working with parents, especially if the counselor's time is too limited for individual sessions. Group members are encouraged to develop an accepting, permissive atmosphere of rapport and trust, allowing the release of participant attitudes, thoughts and

feeling. Some group members may find life more meaningful as they share their experiences with others.

Contracting with families during a crisis to use the post-crisis period to anticipate and prevent future crises is often crucial. Without such guidance, many families may rebound from one crisis to the next, achieving few gains over time except to increased emotional exhaustion and eventual burnout (Walsh & Anderson, 1987). Improved functioning and reduction of stress and conflict in family relationships can be achieved by setting clear, concrete attainable objectives likely to be met during short term contracts. Walsh & Anderson (1987) state that gains can be sustained and setbacks averted in long-term monthly maintenance sessions, in multiple family therapy groups or self-help organizations.

At a minimum intervention with couples is geared to assisting them to better understanding their own value positions toward marriage, examining their level of value-behavior congruency in marriage and the implications of their congruency for their level of satisfaction experienced in marriage, developing insight into the causal conditions that promote or restrain their level of value-behavior congruency, including their exchange orientations and patterns in marriage, and developing skills and resources to better realize their individual and collective goals in marriage (Bowen, 1991).

This approach leads to an interactional process view of marital dynamics that has significant implications for marital enrichment. Spouses within the same marriage may not want the same things from marriage. Therefore, it is important to focus on the values of individual spouses, the level of value congruency between spouses in the marriage and value differences across couples. These differing value orientations pose implications for desired marital related outcomes at the level of the individual and the dyad (Bowen, 1991).

Assuming an ecosystem perspective, the focus of the program will be the interface of the family, the child's special needs; the interactions of the variables, and the influence these factors have on the marital relationship.

THE PROGRAM

I RECRUITING PARTICIPANTS

The participants for the group are being recruited from a variety of sources. Letters were sent to all families of children with special needs registered in the programs of Renfrew Educational Services (Appendix I). In addition to this, notices were sent to two other community programs serving similar population, to the Alberta Children's Hospital, and to some of the referring pediatricians for our agency (Appendix II). The group has also been advertised in our parent newsletter.

A few couples were also identified by the Family Support Worker as being able to benefit from this program, and it was suggested to them directly that they consider attending.

II PROGRAM OUTLINE

WEEK I - PREGROUP

All couples who registered are interviewed by the Family Support Worker. Each person was asked to complete the Dyadic Adjustment Scale (DAS) (Appendix III). Couples were asked what their expectations were. The Family Support Worker clarified the purpose of the group and asked for a commitment for attendance.

WEEK II - INTRODUCTION

1. Welcome

2. Establish Group Rules

- Confidentiality - No judging
- Right to pass - No cross talking
- If you can not attend, call either of the facilitators

3. Present Group Agenda

4. Introductions

- Participants are asked to pair off with someone they are not familiar with. From their interaction they are to get the other person's name, a description of their family, how long they have been in their relationship, what type of work they do, and what they would most like to get out of the group. They are invited into the group to introduce the person they were paired with.

5. Film - Young Adult Institute - "Children with Special Needs" video series - #33 Having a Developmentally Disabled Child.

6. Discussion - similarities and differences from member's experiences.

7. Closure

8. Homework - go on a date! Men pick what to do - women arrange child care.

WEEK III - THEORY

1. Check-in

- any unfinished business from last week
- any thing relevant which came up during the week

2. Review from last week

3. Explanation of the Adjustment Process

- denial
- guilt
- depression
- anger
- bargaining
- acceptance

4. Identify times when crisis can occur

- the birth of a child with special needs
- time of diagnosis
- when child does not achieve normal developmental milestones
- when child develops behavior problems peculiar to their special need
- times of rejection or stigmatization

5. Family life cycle

- courtship
- marriage
- children
 - preschool
 - school age
 - adolescents
- launching
- reorganization of couple

- mid-life
- retirement

6. Break into diads

- with partner discuss one issue which the adjustment process can be applied
- identify one ongoing issue
- identify one issue which there is a difference in where the spouse is at in the process.

7. Wrap up and Closure

8. Homework - go on a date! Women pick what to do - men arrange childcare.

WEEK IV - FEELINGS

1. Check in

- unfinished business from last week
- questions, comments

2. Feelings

- complete the "You are responsible for your feelings" questionnaire (Appendix III) from Bower & Bower (1976).

3. Discuss response to questionnaire with spouse.

4. Complete the list on changes in feelings and thoughts (Appendix IV).

5. Discuss as a group the changes experienced in feelings and thoughts since birth of the child or diagnosis of the child's special need.

6. Closure and wrap-up.

7. Homework - set aside one hour this week and discuss three ways your family will be different than it is now 2 years from now; 5 years from now; and 10 years from now.

WEEK V - COMMUNICATION

1. Check-in

- unfinished business
- issues, concerns, questions from last week

2. Video - Young Adult Institute - Children With Special Needs - #13 Issues of Family Life - Part I.

3. Break into two groups - men and women

- assign a recorder in each group
- In the video parents openly discuss that they had feelings which they were afraid to share with their spouse. Each group is to list feeling that members were afraid to share with their partners.

4. Sending and receiving messages (hand out) (Appendix V)

5. Exercise in active listening.

- Each couple pick a partner A and a partner B. Partner 'A's are the active listeners, partner 'B's are the talkers. 'A's practice active listening while their partners talk for three minutes on any topic. After three minutes partner 'A's continue to be the listeners but now are asked to do a multiplication table in their head while partners continue to talk. After three minutes partners switch roles and repeat the sequence.

6. Discuss the experience from the exercise. Relate to real situations.

7. Wrap-up

8. Homework - each evening set aside ten minutes. Each person take five minute turns at active listening and talking. Use a timer and each person must use all their time (if there is nothing to say or if you can't think of anything to say the time passes in silence). Use the 'Sending Messages' from the handout (Appendix VI) as a guideline when it is your turn to talk.

WEEK VI - CONFLICT RESOLUTION & PROBLEM SOLVING

1. Check in
 - any questions or comments about last week?
 - who did their homework - what was the experience like?
2. Introduce Conflict and problem solving topic.
3. Complete the 'Conflict questionnaire' (Appendix VII).
4. Pair off with spouse and compare answers.
5. Discuss Problem Solving Model
 1. Identify the problem
 2. Brainstorm solutions
 3. Short-list the solutions to three, four or five
 4. Explore the positives and negatives of each possible solution
 5. Pick one, implement and evaluate
6. Break into two groups (husbands and wives not in same groups)
 - Each member writes out a problem they have
 - Pick one problem
 - Define the problem clearly
 - As a group, members brainstorm solutions
 - Short-list solutions
 - Explore pros and cons of each
 - Continue until all problems are gone through
7. Back in the large group - discuss the process and its practicality for every day problem solving.
8. Closure
9. Homework - During the week, identify a problem, go through the problem solving model with your spouse, implement solution and evaluate outcome.

WEEK VII - GENDER ISSUES, ROLES & RESPONSIBILITIES, SELF-ESTEEM

1. Check in

- any questions from last week?
- who did their homework and how what was the experience?

2. Discuss some of the gender issues which typically present in parenting and in traditional families. Identify some gender differences in coping with stress.

3. Video - Young Adult Institute - Children With Special Needs - #15 Fathers.

4. Break into two groups - men in one group and women in the other.

Identify gender issues you are familiar with.

Discuss how these gender issues are affected by having a child with special needs.

Do fathers cope differently with the reality of having a child with special needs than mothers do? If so how and why?

What effect has having a child with special needs effected your self-esteem? Your spouses?

5. Both groups together share their discussions.

6. How have you grown personally from parenting a child with special needs?

7. Closure

8. Homework: Watch the video Lighten Up with Sandy Queen.

Tomorrow create a list of positive affirmations for yourself which contains at least five items.

Repeat these to yourself three times each day.

Each day add a new affirmation.

WEEK VIII - OTHER CHILDREN, EXTENDED FAMILY, BUILDING
SUPPORT SYSTEMS, SETTING BOUNDARIES

1. Check in:
 - any questions from last week?
 - what were people's experience with the homework exercise?
2. Discuss some of the common concerns of siblings of children with special needs. Common worries are:
 - being responsible for brother or sister in the future
 - is the special need contagious
 - resentment/jealousy of the extra time required by child
 - explaining their brother or sister to friends
 - if parents do not talk about the child's special needs the brother or sister do not feel comfortable asking questions.
3. Video - Young Adult Institute - Children with Special Needs - #17
Having a Disabled Brother or Sister.
4. Ideas on how to talk and treat the siblings of a child with special needs.
5. Complete support questionnaire (Appendix VII)
6. Identify the gaps between the supports you have and the support that you would like to have.
7. Discussion on the influence of extended family members - help or hindrance?
8. Dealing with the reactions of others to a child with special needs can sometimes be difficult. Discuss ways to deal with this situation.
9. Discuss boundaries - individual and family - the effects of poor boundaries - ways of creating strong boundaries
10. Closure

- Would everyone like their phone numbers on a list to be given out next week?

11. Homework - complete the exercise entitled 'Your Relationship Vision' (Appendix VIII)

WEEK IX - WHERE DO WE GO FROM HERE

1. Check in
 - questions from last time?
 - what was the process like going through the exercise of relationship vision?
2. What transitions in the future will be stressful for you as parents of children with special needs?
3. What are the fears associated with these stressful events?
4. What are some of the coping mechanisms which are most useful?
 Write down three things which you do to alleviate stress.
 On a paper make three lines going in each direction - this should make 16 boxes. Mingle with others in the group, share your ideas, and fill the boxes with stress reducers that may work for you.
5. Video - Young Adult Institute - Children With Special Needs - #4 Stress and Coping
6. Nurturing your relationship.
 - Each couple is given an egg and asked to imagine that the egg is their relationship. Describe it as it is now. Discuss what you need to do to take care of it.
7. Share those ideas with the group
8. Review of the material covered in the last eight weeks.
9. Closure

- Give out telephone list
- Give members an opportunity to terminate with the group
- Have each member complete the questions:
 1. The things I found most useful in this group were:
 2. The things I found least useful were:
 3. Things I would have liked to see added to the group or things I would like to see changed are:
 4. Overall rating of the group 1 to 10 (one low - ten high)
 5. Other comments:

WEEK X - FOLLOW-UP

A post group interview will be done with each couple who participated in the group. Individuals will be asked to complete the Dyadic Adjustment Scale. These answers will be compared to those done in week one to determine if there is a measured improvement in the couples perception of their relationship.

During the course of the interview each person will be asked to share any ideas or comments about the group. All group members will be offered a copy of the final report of this project.

CHAPTER V - STRATEGY EMPLOYED - ACTION TAKEN AND RESULTS

The program designed for this project is an eight week group for couples who have a child with special needs. The week prior to the group's start-up was used to meet with the six couples who had registered. During this meeting, couples were able to ask questions about the group and were asked to complete the Dyadic Adjustment Scale (DAS) (Appendix III). At this time couples were also asked to make a commitment to try to attend all eight sessions. The week following the eight week group was used to do follow-up interviews with participants during which time they were asked to provide feedback on their group experience and to address any unfinished business which resulted from the group.

Six couples registered for the program. One couple dropped out because of a conflict with the husband's work schedule. Of the five couples which completed the program, there was about a 90% attendance rate. The ages of the participants ranged from 29 to 42 years, with a difference in the ages of the partners ranging from a few months to 3 years. The couples had been together between 6 and 17 years. Three of the couples had two children, one couple had four children, and one couple had a single child.

Although the group was outlined week by week, there was some deviation from that plan to allow extra time for issues which required more attention.

The objective for the first week was to establish and affirm the context in which the group would operate. In addition to the agenda which had originally been established, a collective list of what the men and women in the group hoped to get from the experience was compiled. This list included:

- to discuss the future of the children
- to have an opportunity to normalize feelings
- to get ideas on how to strengthen the couple relationship
- to look at issues which may arise for siblings of children with special needs

- to have a chance to meet other parents of children with special needs and to share stories
- to have the opportunity for open communication about problems
- to learn some coping strategies for dealing with difficult situations with spouses and families.

This list was consistent with the predetermined objectives of the group which had been established based primarily on information from literature and research.

Two of the couples were not able to attend the first session. (One was the couple who dropped out of the group). The second couple who were not there during the first week were given an overview of the evening prior to the next week's meeting.

For the second week, all five couples were present. Only two of the couples had followed up on their homework of going on a date. The objective of this week was to understand some of the theoretical perspectives pertaining to, and effected by, having a child with special needs. This week's material was focused on theory, looking at the adjustment process, times when families go into crisis, family life cycle, and the impact thereof of having a child with special needs. Individuals were able to identify their own processes of adjustment and were able to apply the theory to their own situations.

Prior to closing the session this week, there was a discussion on how the couples could be successful with this week's homework assignment. Couples were able to give each-other suggestions on things to do and childcare arrangements, and two couples decided to go out together. This proved to be successful as, the next week, all couples had been successful with their homework.

The objective for the third week of the group was to identify feelings associated with having a child with special needs and examine how these feelings are expressed or repressed. During the check-in there were some comments pertaining to the adjustment process and situations which had arisen during the week for two of the couples.

During the discussion on how feelings and thoughts had changed since the birth or diagnosis of their child with special needs, the parents described how their perceptions had changed of the medical profession, their family and friends, and with regard to the

in being able to access services. Parents talked about how their relationship changed with family members and friends when these people found out that the child had special needs. They shared that some of the reactions were very supportive and others were distant and uncertain. A common phenomenon was that all the parents in the group felt that having a child with special needs had heightened their awareness about the issues and needs of others. They reported being much more empathetic towards others.

The objectives of the forth week of the program was to identify the relationship between feelings and communication, and to look at improving communication patterns. During this session, most of the parents were very open about their feelings. One parent talked about the anger he felt towards his partner because she insisted that there was something different about their son from the time he was born. When her fears were confirmed by a doctor, this husband's anger became self-directed as he asked the question "how come you can see it and I can't?". He stated that he later shifted his anger towards the doctor. In looking back, he identified that most of his denial was imbedded in the stereotypes associated with 'handicapped' which he grew up with. When he was in that mind space he did not want to talk or hear about any of the possible issues concerning his son. Another of the fathers talked about the fear of the unknown, stating that as long as his son continued to make progress, he was able to deny that his child had special needs. He had adopted a theory of "worry does not make it better". This same father later shared with the group how difficult it was to look at any negative information when you were trying so hard to be positive. He identified having been very frustrated with his wife who was always looking for answers.

One mother shared her feelings of being ashamed and embarrassed about feeling selfish, and felt that this kept her from being honest as to what her needs were. Her husband talked about feeling jealous towards the child over the additional time required to care for the child - taking time away from himself. Most parents identified with the analogy of being on a rollercoaster ride, with all their ups and downs, twists, turns, and

analogy of being on a rollercoaster ride, with all their ups and downs, twists, turns, and unsuspected loops. The parents talked about the fears of having their child live with a label, the fears of the unknown, and the difficulty of trying to be optimistic all the time. They felt that there was an expectation placed on them to always be positive and hopeful.

Most of the couples did really well with the 'Active Listening' exercise. One couple were surprised at the content of the conversation which came from the opportunity just to talk and listen to the other. The wife was particularly surprised at the depth of her husband's sharing, and felt that the exercise gave him the chance to communicate at a 'deeper level' than he had before. Another couple had a very difficult time with the exercise. It was especially difficult for the wife to listen while her husband talked. Although the exercise was for each partner to actively listen for 3 minutes, she could not resist responding, directing the topic - which was suppose to be his choice - and proceeded to interrupt and judge things he said. In the discussion of the exercise, this husband identified that this was typical of their communication and that he often felt that what he had to say was of no value and not important. His wife stated that this was an area which she would have to work at.

The following week during check-in this couple stated that they had worked on their homework on a "fairly regular" basis - the homework was to take five minutes each day and each take a couple minutes to practice 'active listening' while the other spoke. They stated that they would need more practice in this area. Other couples had either not followed through with the homework, or admitted to making a minimal effort at it.

The objectives this week were to identify the role of conflict in relationships and to explore a problem solving model. This started with each individual identifying their own, and their partner's, attitude towards conflict. All couples were fairly accurate in their assessment of each other's attitude towards conflict. Most agreed that conflict itself was not necessarily a negative thing, rather it was how it was dealt with that could make it negative. The proposed agenda for this week was followed quite closely except that,

through the problem solving model with it, the group stayed together and went through a couple of different scenarios together. Group members felt that this is a very practical model and that it would be very useful, providing one could remind one's self to do it.

The objectives for the sixth week of the group - week seven of the project - were to explore gender issues, roles and responsibilities, and to identify the impact on self-esteem of having a child with special needs. The proposed agenda for this week was altered slightly due to problems with the video which was scheduled to be shown. This allowed for more time for the discussion on gender issues, to explore differences in how fathers and mothers cope with the reality of having a child with special needs, and the effect that this has had on the self-esteem of the parent. The group reached a consensus that there are differences in the ways men and women cope with the various issues of having a child with special needs. Some of the men shared the difficulty they had in discussing their child's needs with their peers, identifying that this makes it difficult to establish a support system. Some of the men and women stated that it was sometimes more necessary for women to cope with the reality, as they are the ones typically confronted with the information of a child's special needs and spent the most time with their children - in this group all the mothers were the primary care givers. Accordingly, women have little opportunity to escape from the realities of having a child with special needs. The discussion also examined the socialization of men and women, and how they are socialized differently, especially in the area of having society's permission to express emotions. The idea that, characteristically, men want to fix problems, whereas women want to understand them, seemed to be consistent with the experiences of the people in the group. All parents reported that, in some way, their self-esteem had been negatively effected as a result of having a child with special needs, most often in that they have had to question their ability to meet the challenges of parenting the child. In addition to this, however, each person expressed that they had learnt a lot from being a parent of a child with special needs and were better people because of it.

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Initially, the plan was to have the couples each take home a copy of the video 'Lighten Up' for their homework. This plan was revised and the homework was to work on positive affirmations. The video was rescheduled to be shown the last week of the group.

The following week most parents expressed that they found it very awkward giving themselves the positive affirmations. As is often the case, all were more comfortable with giving someone else positive comments than with identifying any positive statements for themselves. With this, each person was given a piece of paper and asked to write down at least five things they liked about themselves or things they were good at. Several members struggled with this, yet each one eventually succeeded. The group was given directions to post these affirmations in an obvious place - fridge door or bathroom mirror - and to tell themselves the affirmations at least once each day. Each person was also instructed to add one new statement to the list at least every-other day.

The objectives for this week were to identify and understand the issues and concerns of siblings of children with special needs; to explore the issues pertaining to those of extended family members; to identify existing and potential support systems, and look at ways of building support systems; and to understand the importance of establishing boundaries and strategies for doing so.

Soon after the group started on this evening's work it became apparent that there were too many items on the agenda. The discussion on the concerns of siblings of children with special needs took a considerable amount of time. There was some concern as to how relevant this topic would be for the couple who only had the one child. They, however, were able to relate the information to their nieces and nephews. It also served as a catalyst for discussion about their reservations of having another child. The couple expressed being very hesitant about having another child as there has yet to be a

child would be easier if they could be assured that their son's special needs were not, in any way, hereditary.

Although the group agreed to go an extra half hour, there was insufficient time to adequately cover the topics of building support systems and dealing with the reactions of others to a child with special needs. The topic of setting boundaries did not get addressed at all.

The last week of the group had a lower energy level than other weeks. One of the couples could not attend the session as their 'typical' child had been diagnosed earlier that day with leukemia. The whole group felt the shock of this news. There was some discussion on what type of support this family might require and what other members of the group could do to help them.

The objectives for this last meeting were to identify future transitions which could potentially be difficult to deal with; to examine various ways of coping with stress; and to explore ways of nurturing the relationship. There were several changes to the proposed agenda for this last meeting. All the couples reported having done some work on the exercise of their relationship vision. The exercise on 'nurturing the relationship' was changed somewhat from what was originally planned. Rather than an egg, each couple was given a seedling plant. They were told that the plant was their relationship and given the instructions to describe it as it is now, to describe it as they would like it to be, and then to talk about what they need to do to get it there. Following this there was a group discussion on what transitions would likely be stressful in the future, with the sharing of coping mechanisms following this. The group then watched the video 'Lighten Up'. After a brief discussion on the video there was a review of the information covered over the past eight weeks, and a look at how this compared to the list which was done the first week as to what they hoped to get out of the group. Group members were then asked to complete a program evaluation (Appendix X). Before the couples left they were

thanked for their participation, given the opportunity to share their feelings about the group and asked to schedule follow-up meetings for the following week.

All couples agreed that it was very useful getting together with other couples and that the focus of the group was very useful. One of the couples expressed that they wished they had been in a group like this two years sooner.

The information on the evaluation forms and that provided in the follow up interviews was very consistent. The only criticism that came up was that some parents spent too much time discussing their child's specific behaviors. Other comments reflected an appreciation for the opportunity to have a place to discuss with partners issues which may have otherwise been avoided, and for the opportunity to hear the feelings and concerns of other couples. For the most part, participants in the group felt that there was a good balance between theory the practical application thereof.

During the follow-up interviews with the couples, one couple identified themselves as being 'at risk' of separation. They have had several issues throughout their marriage, all of which seem to have been further complicated since the birth of their son with down syndrome. This couple was very grateful for the group and stated that they are going to continue to work on some of the strategies we discussed in the group. Both partners expressed that the communication part of the program was the most beneficial for them. It was suggested to them that they may want to pursue some further couple counseling.

Other individuals identified different parts of the program as being the most beneficial. A couple of people commented that they enjoyed breaking into groups with men in one, and women in the other, stating that it was particularly useful to discuss specific issues with just the other mothers or fathers. One parent found it most useful to hear about other parent's challenges, while another appreciated hearing other parents voice similar feelings and concerns to their own. One of the participants enjoyed the videos the most, while another stated that the best part of the group was having an

opportunity to discuss issues with her husband which have previously been avoided. All individuals stated that they had learned a lot in the group and would recommend the group to any couple who had a child with special needs.

The Dyadic Adjustment Scale (DAS) - Appendix III proved to be limited in its usefulness for this project. The scale was initially selected as it was described as being able to measure four aspects of a relationship; dyadic satisfaction, dyadic cohesion, dyadic consensus, and affectional expression. By its design, this scale should be able to do this. However, there are some significant discrepancies in the way the instrument is to be scored and the interpretation of those scores. According to the description, this tool scores between 0-151 with higher scores reflecting a better relationship than lower scores. This will not work, however, as there are low ratings attached to positive statements and high ratings given to negative statements. There is no direction for reverse scoring, but, items 1 to 15, 18, and 19 should be reverse scored. By doing so, however, the score could go up to 167. In addition to this, items 29 and 30 do not have any value attached to them.

The individual scores for the participants in this group ranged from 119 to 145. In all but one couple - whose score differed by one point - the men had higher scores than did the women. In most cases these differences were only a few points except for one couple which had a 17 point difference. This confirms some of the observed differences in the way the individuals in this couple perceive their relationship.

Although limited, this scale was useful as a means of comparison for partners about their relationship. Because of discrepancies in scoring, however, the tool was not used as a post-test to measure any changes which may have taken place as a result of their experience in the group. For the next group, this tool will be replaced by the Family Coping Inventory (FCI) (1981) as developed by H.I. McCubbin and H.M. Patterson. This systematic assessment of family stress, resources and coping will serve as a more useful pre- and post-test measure for this group in the future.

CHAPTER VI - CONCLUSION - IMPLICATIONS AND RECOMMENDATIONS

This project provided a unique and specialized service to parents of children with special needs. The design of the group was very close to a psychoeducational model, providing a blend of support, education, and opportunities to practice new skills. Through the group, parents were able to explore various issues pertaining to having a child with special needs, in the context of how related variables impact their marriage. This provided an opportunity for parents to look at their relationship, their individual roles in that relationship, and the impact that having a child with special needs has had on them as individuals and in their relationship. In addition to exploring the problems and concerns, participants were given a chance to identify and apply strategies and skills for coping with challenges and strengthening their relationships.

Through the process of the group, participants identified a variety of stressors and needs common to themselves as parents of children with special needs. These were consistent with those described in the literature.

The group setting was very conducive to exploring the issues and identifying strategies for coping and enhancing relationships. Typical of most support groups, the couples in this group found it especially useful to be with others who had similar experiences and concerns. This not only helped to normalize their experiences, and assure them that they were not alone, but, it also provided an arena in which they had permission to express themselves, amongst people who could relate to their frustrations, anxieties, and fears. In addition to this, these same people could relate to the celebration of even the smallest of advances made by their children. The group bonded very quickly and, by the second week, individuals were comfortable with sharing their own very personal experiences with the other members of the group.

The structure and content of the project worked well with this group. Members responded favorably to the mix of theory and the practical application thereof. The sequencing of information seemed to flow smoothly except that, at times, there was not

enough time to more thoroughly delve into some of the issues . The format of the next group will be such that each session will run a half-hour longer, and the group will be extended another two weeks to accommodate all the information and to provide more time to carry out the practical exercises. In doing so, this will accommodate a separate session to look at sibling issues and concerns, one specifically to look at establishing support systems, and a session reserved to explore coping and stress management strategies.

In order to better accommodate the process, and to encourage the completion of homework assignments, all handouts and exercises will be compiled into a work book and given to the participants at the time of the pre-group interview. This will also give couples a chance to review all the information prior to starting the group.

From the information provided on the evaluations and the comments made during the follow-up interviews, it can be concluded that the program successfully met the objectives. Overall, parents felt very good about their involvement with the program and identified that their participation in the group was beneficial to their relationships. Several of the participants stated that it would have been useful to have been through this type of group at a time closer to the diagnosis of their child's special needs. This would have assisted them in weathering some very stormy times as a couple.

Programs which offer support groups for parents of children with special needs should consider expanding their focus to include identifying the impact that having a child with special needs has on a relationship and to provide services, similar to this project, to address these issues. Parents who understand the impact of their child's special needs on their relationship will be better prepared to develop supportive and understanding relationships with their partners. Ultimately, this will benefit the child as the parents in healthy relationships will be able to better cope with the day-to-day challenges of parenting a child with special needs.

Since the start of this project there has been considerable interest generated in the group both internally, and from other agencies and programs. There are currently six couples on a wait list for the next group, scheduled to start in October 1995. The completion of the second group will provide supportive documentation to the benefits of such a group. At this time, the plans are to compile this information and put forth a proposal to present the project at the annual conference of the Council for Exceptional Children, Division of Early Childhood.

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APPENDICES

APPENDIX I

Letters to families



Renfrew Early Childhood Services School (Est. 1974)

731 - 13th AVENUE N.E., CALGARY, ALBERTA T2E 1C8

TELEPHONE (403) 277-6441 - Northeast

(403) 276 2211 - Northwest

(403) 225-2144 - South

FAX (403) 276 9875

MEMO

March 28, 1995

TO: PARENTS OF CHILDREN WITH SPECIAL NEEDS

From: Richard Gregory - Family Support Worker.

I am very pleased to offer a new program specifically for parents of children with special needs to explore the effects that having a child with special needs has on the relationship of the parents. Research is varied, but some studies indicate that couples who have a child with special needs have a divorce rate up to three times higher than that of parents with typically developing children.

Traditionally, programs offered to parents focus on what they need to do for their child. This program, more specifically, looks at the relationship issues between the parents and how these are complicated by the additional stressors of having a child with special needs. Topics discussed in the group will include: understanding the impact of your child's special needs on your relationship, coping strategies for dealing with ongoing stressors, communication and relationship building, and identifying support systems.

The group will run for eight Monday evenings, 7 to 9 p.m., starting April 24th through to June 12th. The group will be co-facilitated by Jan Gordon, a therapist from the Pastoral Institute, and Richard Gregory.

There will be a maximum of ten couples in the group and we ask that both parents commit to attend all eight sessions. Participation in the group is confidential. There is no fee for this service.

For further information, or to register for the group, please call Richard at 276-2211.

APPENDIX II

Notices of program to community agencies



Renfrew Educational Services

P.O. BOX 52013, EDMONTON TRAIL R.P.O., CALGARY, ALBERTA T2E 8K9

TELEPHONE (403) 276-2211 - Northwest (Administrative Center)

(403) 247-6200 - Bowness

(403) 277-6441 - Northeast

(403) 225-2144 - South

(403) 230-7007 - Northeast (Daycare)

FAX (403) 276-9875

SPECIAL NOTICE

RENFREW EDUCATIONAL SERVICES, in partnership with the PASTORAL INSTITUTE, are offering a program specifically for parents of children with special needs to explore the effects that having a child with special needs has on the relationship of the parents. Research is inconsistent, but some studies indicate that couples with a child with special needs have a divorce rate up to three times higher than that of parents with typically developing children.

Topics discussed in the group will include: understanding the impact of a child's special needs on the relationship between the parents, coping strategies for dealing with the ongoing stressors of having a child with special needs, communication and relationship building, and identifying support systems.

The group will run for eight Monday evenings, 7 to 9 p.m., starting April 24th through to June 12th. Jan Gordon MSW, a therapist from the Pastoral Institute, and Richard Gregory BSW RSW, the family support worker at Renfrew Educational Services will co-facilitate the group. There will be a maximum of ten couples in the group and both parents are asked to commit to attend all eight sessions. Participation in the group is confidential. There is no fee for this service.

For further information, or to register for the group, please call Richard at 276-2211.

APPENDIX III

Dyadic Adjustment Scale (DAS)

DYADIC ADJUSTMENT SCALE (DAS)

AUTHOR: Graham B. Spanier

PURPOSE: To assess the quality of marriage or similar dyads.

DESCRIPTION: This 32-item instrument is designed to assess the quality of the relationship as perceived by married or cohabiting couples. The instrument was designed to serve a number of needs. It can be used as a general measure of satisfaction in an intimate relationship by using total scores. Factor analysis indicates that the instrument measures four aspects of the relationship: dyadic satisfaction (DS), dyadic cohesion (DCoh), dyadic consensus (DCon) and affectional expression (AE). The instrument may be adapted for use in interviews.

NORMS: The DAS was developed on a sample of married ($n = 218$) and divorced persons ($n = 94$). The average age of the married people was 35.1 years, while the divorced sample was slightly younger, 30.4 years. The married sample had been married an average of 13.2 years while the average length of the marriages for the divorced sample was 8.5 years. The mean score on the total DAS was 114.8 with a standard deviation of 17.8 for the married sample. The mean for the divorced sample was 70.7 with a standard deviation of 23.8.

SCORING: Three different types of rating scales are used with the DAS. Total scores are the sum of all items, ranging from 0-151. Higher scores reflect a better relationship. The factor items are as follows: DS: 16, 17, 18, 19, 20, 21, 22, 23, 31, 32; DCoh: 24, 25, 26, 27, 28; DCon: 1, 2, 3, 5, 7, 8, 9, 10, 11, 12, 13, 14, 15; AE: 4, 6, 29, 30.

RELIABILITY: As a total score, the DAS has impressive internal consistency, with an alpha of .96. The subscales have fair to excellent internal consistency: DS .94, DCoh .81, DCon .90, and AE .73.

VALIDITY: The instrument was first checked with logical content validity procedures. The DAS also has shown known-groups validity by discriminating between married and divorced couples on each item. The instrument also has evidence of concurrent validity, correlating with the Locke-Wallace Marital Adjustment Scale.

PRIMARY REFERENCE: Spanier, G. B. (1976). Measuring dyadic adjustment: New scales for assessing the quality of marriage and similar dyads, *Journal of Marriage and the Family* 38, 15-28. Instrument reproduced with permission of Graham B. Spanier.

AVAILABILITY: Journal article.

DAS

Most persons have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following list.

- 1 = Always agree
- 2 = Almost always agree
- 3 = Occasionally disagree
- 4 = Frequently disagree
- 5 = Almost always disagree
- 6 = Always disagree

- ___ 1. Handling family finances
- ___ 2. Matters of recreation
- ___ 3. Religious matters
- ___ 4. Demonstrations of affection
- ___ 5. Friends
- ___ 6. Sex relations
- ___ 7. Conventionality (correct or proper behavior)
- ___ 8. Philosophy of life
- ___ 9. Ways of dealing with parents or in-laws
- ___ 10. Aims, goals, and things believed important
- ___ 11. Amount of time spent together
- ___ 12. Making major decisions
- ___ 13. Household tasks
- ___ 14. Leisure time interests and activities
- ___ 15. Career decisions

- 1 = All the time
- 2 = Most of the time
- 3 = More often than not
- 4 = Occasionally
- 5 = Rarely
- 6 = Never

- ___ 16. How often do you discuss or have you considered divorce, separation, or terminating your relationship?
- ___ 17. How often do you or your mate leave the house after a fight?
- ___ 18. In general, how often do you think that things between you and your partner are going well?
- ___ 19. Do you confide in your mate?
- ___ 20. Do you ever regret that you married? (or lived together)
- ___ 21. How often do you and your partner quarrel?
- ___ 22. How often do you and your mate "get on each other's nerves?"

23. Do you kiss your mate?

Every day	Almost Every day	Occa- sionally	Rarely	Never
4	3	2	1	0

24. Do you and your mate engage in outside interests together?

All of them	Most of them	Some of them	Very few of them	None of them
4	3	2	1	0

How often would you say the following events occur between you and your mate?

0 = Never
1 = Less than once a month
2 = Once or twice a month
3 = Once a day
4 = More often

___ 25. Have a stimulating exchange of ideas

___ 26. Laugh together

___ 27. Calmly discuss something

___ 28. Work together on a project

These are some things about which couples sometimes agree and sometimes disagree. Indicate if either item below caused differences of opinions or problems in your relationship during the past few weeks. (Check yes or no)

Yes No 29. Being too tired for sex

Yes No 30. Not showing love

31. The numbers on the following line represent different degrees of happiness in your relationship. The middle point, "happy," represents the degree of happiness of most relationships. Please circle the number that best describes the degree of happiness, all things considered, of your relationship.

0	1	2	3	4	5	6
Extremely Unhappy	Fairly Unhappy	A Little Unhappy	Happy	Very Happy	Extremely Happy	Perfect

32. Please circle one of the following statements that best describes how you feel about the future of your relationship.

- 5 I want desperately for my relationship to succeed, and *would go to almost any length* to see that it does.
- 4 I want very much for my relationship to succeed, and *will do all I can* to see that it does.
- 3 I want very much for my relationship to succeed, and *will do my fair share* to see that it does.
- 2 It would be nice if my relationship succeeded, but *I can't do much more than I am doing now* to help it succeed.
- 1 It would be nice if it succeeded, but *I refuse to do any more than I am doing now* to keep the relationship going.
- 0 My relationship can never succeed, and *there is no more that I can do* to keep the relationship going.

APPENDIX IV

Questionnaire: You are responsible for your own feelings

(Bower & Bower, 1976)

Feelings are neither right nor wrong. They are internal messages (stomach fluttering, heart pounding, muscle tension) that tell you your personal truth. "This is right with me" or "This is not right with me."

Respect feelings and do not be ruled by them. Feelings are connected to you thought and belief systems. Wise decisions are not made on feelings alone but use thoughtful analysis of the external world and checking your beliefs about the situation. Do you believe, "My partner exists to make me happy"? This may create a feeling of disappointment and inappropriately hold your partner responsible.

YOU ARE RESPONSIBLE FOR YOUR FEELINGS

No one makes you feel any emotion. You may experience a certain feeling that gets triggered by something your partner says or does. You are then responsible to acknowledge the feeling, share it with your partner and deal with it. "You make me feel angry" really means "I feel angry when.....(my needs and wants aren't satisfied)".

1. Put a star beside the feeling words you find difficult to express.
2. Put a check mark beside the feeling words you think your partner finds difficult to express.
3. Discuss the reasons for these difficulties and what might make it easier to express these feelings in the future.

Some basic feelings include:

sad/hurt angry/mad afraid/fear happy/glad

Use a variety of feeling words to express yourself:

☐ lonely	☐ impatient	☐ unsure	☐ warm
☐ neglected	☐ cross	☐ nervous	☐ content
☐ crushed	☐ disappointed	☐ scared	☐ pleased
☐ rejected	☐ resentful	☐ powerless	☐ trusting
☐ abused	☐ aggravated	☐ defensive	☐ delighted
☐ depressed	☐ bitter	☐ vulnerable	☐ terrific
☐ devastated	☐ enraged	☐ terrified	☐ thrilled

Enrich your vocabulary
and marriage by daily
sharing your feelings

APPENDIX V

Questionnaire: Changes in feelings and thoughts since birth or diagnosis of your child with special needs.

LOOK AT EACH ITEM ON THIS LIST AND WRITE HOW YOUR FEELINGS AND THOUGHTS HAVE CHANGED TOWARDS EACH OF THESE SINCE THE BIRTH OF YOUR CHILD.

1. SELF

2. PARTNER

3. CHILD

4. SOCIETY

5. MEDICAL PROFESSION

6. RELIGION

7. FRIENDS

8. OTHER FAMILY MEMBERS

APPENDIX VI

Handout - Sending and Receiving Messages

Communication is the sending and receiving of messages. Your ability to communicate largely determines your personal and coupleship happiness. Clear and open communication is essential for problem solving in marriage.

Sending Messages

Express your observations, thoughts, feelings and wants by:

- beginning sentences with "I"
- avoiding "you" statements which tend to shame and blame
- avoiding expressions like: should, always, never, everything, everybody, etc.

Receiving Messages

Actively listen to your partner by:

- maintaining eye contact and accepting posture
- allowing partner to finish speaking
- using encouragers like "uh-huh," "I'm listening," etc.
- paraphrasing by restating in your own words what you thought you heard, "I think you're saying," "I want to understand you correctly. Are you saying that....," etc.
- perception checking by reflecting the feelings you think are behind the message. "I guess you are feeling...," "That must have been very upsetting for you."

Responsible communication occurs when assertiveness skills are utilized. Marriages can be enhanced when the partners avoid the pitfalls of passive and aggressive behaviours and choose to come from an assertive position.

Assertive:

Involves expressing your thoughts, feelings, beliefs and wishes in direct, brief, honest and appropriate ways which respect both partners' rights.

Passive:

Involves not expressing or minimally expressing your thoughts, feelings, beliefs and wishes in an apologetic and self-demeaning manner and in a way that your partner can easily ignore them. Your partner's rights are honoured while your own are violated.

Aggressive:

Involves forcefully expressing your thoughts, feelings, beliefs and wishes in a controlling and dishonest manner. Your rights are honoured while your partner's are violated.

A Bill of Marital Rights

You have the right to:

1. Be treated with respect by your partner.
2. Have and express your own beliefs, thoughts and feelings.
3. Be listened to and taken seriously by your partner.
4. Set your own priorities (establishing what is important to you) in co-operation with your coupleship priorities (establishing what is important for your marriage).
5. Say "no" and "yes" without feeling guilty or needing to explain.
6. Ask for what you want from your partner.
7. Make choices and be responsible for the results.
8. Change your mind and not be teased when you do.
9. Say "I don't know" or "I don't want to."
10. Choose not to assert yourself or say "I pass."

DO'S

DON'TS

"D" Describe

Do describe the other person's behaviour objectively.

Don't describe your emotional reaction to it

Do use concrete terms.

Don't use abstract or vague terms.

Do describe a specified time, place and frequency of the action.

Don't generalize for "all time".

Do describe the action, not the "motive".

Don't guess at another person's motives or goals.

"E" Express

Do express your feelings.

Don't deny your feelings.

Do express them calmly.

Don't unleash emotional outbursts.

Do state feelings in a positive manner, as relating to a goal to be achieved.

Don't state feelings negatively, making put-downs or attack.

Do direct yourself to the specific offending behaviour, not to the whole person.

Don't attack the entire character of the person.

"S" Specify

Do ask explicitly for change in the other person's behaviour.

Don't merely imply that you'd like a change.

Do request a small change.

Don't ask for too large of a change.

Do request only one or two changes at one time.

Don't ask for too many changes.

Do specify the concrete actions you want to see stopped, and those you want to see performed.

Don't ask for changes in nebulous traits or qualities.

the other person can meet
your request without
suffering large losses.

person's needs, or ask
only for your satis-
faction.

Do specify (if appropriate)
what behaviour you are
willing to change to make
the agreement.

Don't consider that
only the other person
has to change.

"C"
Consequences

Do make the consequences
explicit.

Don't be ashamed to
talk about rewards and
penalties.

Do give a positive reward
for change in the desired
direction.

Don't give only punish-
ments for lack of
change.

Do select something that
is desirable and rein-
forcing to the other
person.

Don't select something
that only you might
find rewarding.

Do select a reward that
is big enough to maintain
the behaviour change

Don't offer a reward you
can't or won't deliver.

Do select a punishment of
a magnitude that "fits the
crime" of refusing to
change the behaviour.

Don't make exaggerated
threats.

Do select a punishment
that you are actually
willing to carry out.

Don't use unrealistic
threats or self-defeating
punishments.

APPENDIX VII

Questionnaire: Attitudes Towards Conflict

(Bower & Bower, 1976)

CONFLICT QUESTIONNAIRE

A. Circle the number which best represents your position along a continuum of attitudes toward conflict. Ask yourself how your behavior reflects these attitudes.

- | | | |
|---|---------------|--|
| 1. Conflict leads to destruction | 1 2 3 4 5 6 7 | Conflict leads to growth |
| 2. Conflict leads to rational learning | 1 2 3 4 5 6 7 | Conflict leads to irrationality |
| 3. Conflict leads to confusion | 1 2 3 4 5 6 7 | Conflict leads to clarification |
| 4. Conflict leads to being avoided | 1 2 3 4 5 6 7 | Conflict leads to being confronted |
| 5. Conflict is basically a struggle for power | 1 2 3 4 5 6 7 | Conflict is basically an indication for change |

B. Now place an 'X' on the number which best represents your partner's attitude toward conflict. What kind of behaviors do you perceive to be indications of these attitudes?

C. Complete the sentences:

1. The most threatening aspect of conflict in my relationship with my partner is

2. When it comes to stating my feelings about a difference with my partner, I

3. When we have an argument I usually _____

4. Our conflicts usually end when _____

5. I express my anger by _____

6. My partner expresses his/her anger by _____

7. When my partner expresses his/her anger I feel _____

From Bower, S.A. & Bower, G.H. (1976). Asserting Yourself: A Practical Guide for Positive Change. Reading, M.A.: Addison-Wesley.

Competing:

- **AGGRESSIVE** and uncooperative
- destructive to a coupleship as one wins and other loses.

Accommodating

- **PASSIVE** and self sacrificing
- destructive to a coupleship as one is giving up on SELF

Avoiding

- avoids addressing the rights of both partners
- destructive to a coupleship as it keeps partners stuck

Compromising

- settling on a solution that is not fully satisfying
- splits the difference to maintain marital harmony

Collaborating

- **ASSERTIVE**, both partners, work as a team
- expressing, listening and problem solving skills are used.

CONSTRUCTIVE	DESTRUCTIVE
Establish the real issue.	Don't clarify the real issue.
Stick to the point.	Don't stick to the point.
Listen attentively.	Demand to be listened to.
Understand each other in both content and feelings.	Do not understand each other in both content and feelings.
Provide support to partner.	Attack vulnerabilities.
Be sensitive to each other's points of vulnerability.	Use intimate knowledge to hurt.
Be willing to compromise.	Surrender your own needs or stick firmly to your own position.
Bring up matters as soon as they come to awareness.	Avoid bringing up concerns and let resentment build.
	Name call; make put downs; sneer; blame; threaten; hit; bring up the past; make excuses; get even by withholding sex, affection or anything; withdraw; walk out; or make promises you do not intend to keep.

PROBLEM SOLVING

Identify who OWNS the problem--you or the other person.

A. WHEN THE OTHER PERSON OWNS THE PROBLEM

1. Actively listen.
2. Encourage the other's capability to solve problems.
3. Invite to Problem Solve--"Are you interested in solving **YOUR** problem?"

B. WHEN "I" OWN THE PROBLEM

When I own a problem which was created by an **OTHER'S** behaviour the following steps are recommended:

Step ONE:

Provide Information About the Problem:

DESCRIBE clearly and briefly the disturbing behaviour:

"When I (see, hear, experience) _____"

EXPRESS your feelings about the disturbing behaviour:

"I feel (sad, hurt, angry, used, afraid...) _____"

SPECIFY your desired change in behaviour:

"I want (to see, hear, have done) _____
_____(by what time?)"

If the **OTHER** reacts with strong feelings, utilize your listening skills until he or she has established a thinking and problem solving state.

(Refer to: D.E.S.C. -- from Bower, S. A. & Bower, G. H. (1976). Asserting Yourself: A Practical Guide for Positive Change. Reading, M.A.: Addison-Wesley.)

STEP TWO

INVITATION TO PROBLEM SOLVING:

By negotiating in 'good faith' the *problem* becomes an *opportunity* to enhance the relationship. To support mutual participation and decision making the following need to be considered:

- appropriate and convenient timing for both people
- a positive and caring attitude--"this relationship is valuable" and deserves commitment, trust and effort

INVITE the other to problem solve.

"When are you willing to talk to me about how to solve this problem of MINE?"

1. Show Mutual Respect.
 - a) Proceed with care. Decide what words or topics are **OK** and **NOT OK** to include. Decide on a time frame.
 - b) Pinpoint the **REAL** issue. This may include identifying a feeling such as 'insecure', 'neglected', 'manipulated', 'used' or 'disrespected'.
2. Generate a number of options of action. Be creative and have at least **THREE** ideas. Be precise in describing what will be **DONE** by whom and when.
3. Seek **areas of agreement** where you can provide mutual support to one another. Examine the advantages and disadvantages of each alternative. Explore ways to adjust the options to make them agreeable to **ALL** parties involved.
4. Choose and commit to the best alternative.
5. Evaluate and review chosen option. Renegotiate if success has not been reached yet.
6. **CÉLEBRATE!**

APPENDIX VIII

Questionnaires - Assistance needed & Helpful sources

(Dunst, Trivette, & Deal, 1988).

Name _____ Date _____

Listed below are people and groups that oftentimes are helpful to members of a family raising a young child. This questionnaire asks you to indicate how helpful each source is to *your family*.

Please circle the response that best describes how helpful the sources have been to your family during the past 3 to 6 months. If a source of help has not been available to your family during this period of time, circle the NA (Not Available) response.

How helpful has each of the following been to you in terms of raising your child(ren):	Not Available	Not at All Helpful	Sometimes Helpful	Generally Helpful	Very Helpful	Extremely Helpful
1. My parents	NA	1	2	3	4	5
2. My spouse or partner's parents	NA	1	2	3	4	5
3. My relatives/kin	NA	1	2	3	4	5
4. My spouse or partner's relatives/kin	NA	1	2	3	4	5
5. Spouse or partner.	NA	1	2	3	4	5
6. My friends.	NA	1	2	3	4	5
7. My spouse or partner's friends.	NA	1	2	3	4	5
8. My own children	NA	1	2	3	4	5
9. Other parents	NA	1	2	3	4	5
10. Co-workers	NA	1	2	3	4	5
11. Parent groups	NA	1	2	3	4	5
12. Social groups/clubs.	NA	1	2	3	4	5
13. Church members/minister	NA	1	2	3	4	5
14. My family or child's physician	NA	1	2	3	4	5
15. Early childhood intervention program.	NA	1	2	3	4	5
16. School/day-care center	NA	1	2	3	4	5
17. Professional helpers (social workers, therapists, teachers, etc.).	NA	1	2	3	4	5
18. Professional agencies (public health, social services, mental health, etc.)	NA	1	2	3	4	5
19. _____	NA	1	2	3	4	5
20. _____	NA	1	2	3	4	5

Source: C.J. Dunst, C.M. Trivette, and A.G. Deal (1988). *Enabling and empowering families: Principles and guidelines for practice*. Cambridge, MA: Brookline Books. May be reproduced.

Listed below are 20 different types of assistance which people sometimes find helpful. This questionnaire asks you to indicate how much you need help in these areas.

Please circle the response that best describes your needs. Please answer all the questions.

To what extent do you feel it would be helpful to have access to the following types of help or assistance:		Never	Once in a While	Sometimes	Often	Quite Often
1.	Someone to talk to about things that worry you	1	2	3	4	5
2.	Someone to provide money for food, clothes, and other things	1	2	3	4	5
3.	Someone to care for your child on a regular basis	1	2	3	4	5
4.	Someone to talk to about problems with raising your child	1	2	3	4	5
5.	Someone to help you get services for your child	1	2	3	4	5
6.	Someone to encourage you when you are down	1	2	3	4	5
7.	Someone to fix things around the house	1	2	3	4	5
8.	Someone to talk to who has had similar experiences	1	2	3	4	5
9.	Someone to do things with your child	1	2	3	4	5
10.	Someone whom you can depend on.	1	2	3	4	5
11.	Someone to hassle with agencies or businesses when you can't.	1	2	3	4	5
12.	Someone to lend you money	1	2	3	4	5
13.	Someone who accepts your child regardless of how (s)he acts.	1	2	3	4	5
14.	Someone to relax or joke with	1	2	3	4	5
15.	Someone to help with household chores.	1	2	3	4	5
16.	Someone who keeps you going when things seem hard	1	2	3	4	5
17.	Someone to care for your child in emergencies or when you must go out	1	2	3	4	5
18.	Someone to talk to you when you need advice	1	2	3	4	5
19.	Someone to provide you or your child transportation.	1	2	3	4	5
20.	Someone who tells you about services for your child or family	1	2	3	4	5

Source: C.J. Dunst, C.M. Trivette, and A.G. Deal (1988). Enabling and empowering families: Principles and guidelines for practice. Cambridge, MA: Brookline Books. May be reproduced.

APPENDIX IX

Exercise: Your Relationship Vision

(Bowen, 1991)

Exercise 1: Your Relationship Vision

Time: Approximately 60 minutes.

Purpose: This exercise will help you see the potential in your relationship.

Comments: Do this exercise together.

Directions

1. Take out two sheets of paper, one for each of you. Working separately, write a series of short sentences that describe your personal vision of a deeply satisfying love relationship. Include qualities you already have that you want to keep and qualities you wish you had. Write each sentence in the present tense, as if it were already happening. For example: "We have fun together," "We have great sex," "We are loving parents," "We are affectionate with each other." Make all your items positive statements. Write "We settle our differences peacefully" rather than "We don't fight."

2. Share your sentences. Note the items that you have in common and underline them. (It doesn't matter if you have used different words, as long as the general idea is the same.) If your partner has written sentences that you agree with but did not think of yourself, add them to your list. For the moment, ignore items that are not shared.

3. Now turn to your own expanded list and rank each sentence (including the ones that are *not* shared) with a number from 1 to 5 according to its importance to you, with 1 indicating "very important" and 5 indicating "not so important."

4. Circle the two items that are most important to you.

5. Put a check mark beside those items that you think would be most difficult for the two of you to achieve.

6. Now work *together* to design a mutual relationship vision similar to the following example. Start with the items that you both agree are most important. Put a check mark by those items that you both agree would be difficult to achieve. At the bottom of the list, write items that are relatively unimportant. If you have items that are a source of conflict between you, see if you can come up with a compromise statement that satisfies both of you. If not, leave the item off your combined list.

Our Relationship Vision

<i>Bill</i>		<i>Jenny</i>
1	We have fun together.	1
1	We settle our differences peacefully.	1
1	We have satisfying and beautiful sex.	1
1	We are healthy and physically active.	1
1	We communicate easily and openly.	1 ✓
1	We worship together.	1
1	We are each other's best friends.	1
1	We have secure and happy children.	1
2	We trust each other.	1
1	We are sexually faithful.	1
2	We both have satisfying careers.	2 ✓
2	We work well together as parents.	1
2	We share important decisions.	2
2	We meet each other's deepest needs.	2
3	We have daily private time.	4
3	We feel safe with each other.	2
3	We are financially secure.	4 ✓
4	We live close to our parents.	5 ✓
5	We have similar political views.	3

7. Post this list where you can see it daily. Once a week, at the beginning of your work sessions, read it aloud to each other.

APPENDIX X

PROGRAM EVALUATION
COUPLES GROUP - APRIL 24 TO JUNE 19, 1995

PROGRAM EVALUATION
COUPLES GROUP - APRIL 24 TO JUNE 19, 1995

Please take a few minutes to complete the following evaluation so that we can use your feedback to make any changes necessary to improve the group in the future and maximize participants' experiences thereof.

1. The things which I found most useful about the group were:

2. The things which I found least useful were:

3. Things I would change about the group are:

For the following please read each statement and indicate the extent to which you agree or disagree with the statement using the following ratings:

- 1 = strongly agree
- 2 = moderately agree
- 3 = slightly agree
- 4 = slightly disagree
- 5 = moderately disagree
- 6 = strongly disagree

- ___ 4. The information provided in the group helped me identify some of the stressors I experience as a parent of a child with special needs.
- ___ 5. The information provided in the group helped me to identify how having a child with special needs has impacted my relationship with my partner.
- ___ 6. The group helped me understand where the communication may break down in my relationship.
- ___ 7. I found the theory useful in creating an understanding of some of the issues relevant to having a child with special needs.
- ___ 8. There was a good balance between theory and practical application of ideas and concepts.
- ___ 9. The group provided an opportunity for my partner and I to discuss issues which we may not have otherwise talked about.
- ___ 10. I would be comfortable with recommending this group for other parents of children with special needs.
- ___ 11. The number of sessions was a good number for dealing with the issues.
- ___ 12. Two hours was a good length for each session.
- 13. Other comments:

*Thankyou for your participation and for completing the evaluation.
Jan & Richard*